



Lasrado, Reena, Baker, Sophie, Zubair, Maria ORCID logoORCID:
<https://orcid.org/0000-0001-9199-6576>, Kaiser, Polly, Lasrado, Veena Janith,
Rizzo, Matilda, Govia, Ishtar and Edge, Dawn (2020) Exploring Dementia
Care Systems Across the African Caribbean Diaspora: A Scoping Review
and Consultation Exercise. The Gerontologist, 61 (5). ISSN 0016-9013

Downloaded from: <https://e-space.mmu.ac.uk/626333/>

Version: Accepted Version

Publisher: Oxford University Press

DOI: <https://doi.org/10.1093/geront/gnaa023>

Please cite the published version

<https://e-space.mmu.ac.uk>

Title: Exploring dementia care systems across the African-Caribbean diaspora: a scoping review and consultation exercise

Authors:

Reena Lasrado, Division of Nursing, Midwifery & Social Work, The University of Manchester; +441613067884; reena.lasrado@manchester.ac.uk

Sophie Baker, School of Psychology, Bangor University, Wales, UK; sepaa8@bangor.ac.uk

Maria Zubair, Faculty of Health, Psychology and Social Care, Manchester Metropolitan University; +44161 247 2176; m.zubair@mmu.ac.uk; Orcid ID: 0000-0001-9199-6576

Polly Kaiser, Life Story Network CIC, polly.equallyminded@gmail.com

Veena Janith Lasrado, Regional Centre of Nursing & Midwifery Education, HSE Dublin North, veena.lasrado@hse.ie

Matilda Rizzo, matilda.rizzo@gmail.com

Ishtar Govia, Caribbean Institute for Health Research, The University of the West Indies, Mona Campus; (1-876) 977-6151 ext. 274; ishtar.govia@uwimona.edu.jm; Orchid ID: 0000-0001-6852-102X

Dawn Edge, The University of Manchester, Division of Psychology & Mental Health, dawn.edge@manchester.ac.uk

Abstract

Background and Objectives

Understanding the influences of marginalised cultural and social identities as experienced by the African-Caribbean diaspora within the context of dementia care is essential to minimise the gaps in current practice and policy in the health care setting. This study explores the impact of marginalised identities upon the meaning making process, access to services and experience of care provisions through a scoping review and consultancy exercises with key stakeholders.

Research Design

Fourteen databases were searched using key terms. Primary studies in English, any year, study design and country of origin were eligible. Titles, abstracts and full texts were screened for inclusion and data were extracted in stages. Thematic analysis was performed and the findings were discussed in a series of consultation meetings with people with dementia, carers and health care professionals in Manchester (UK) and Jamaica.

Results

The scoping review retrieved n=1989 research articles. Nineteen were included, most were qualitative (n=14), three quantitative and two mixed method. The findings revealed limited insight into cultural and multiple individual identities in explaining conceptualisation and service access. Consultation meetings confirmed these findings and highlighted differences in healthcare services and systems in the UK and Jamaica.

Discussion

This study suggests there is a complex interaction of socio-cultural processes that marginalise African-Caribbean persons in and across various national settings within the context of dementia care. The study highlights the importance of acknowledging and addressing how prevalent racialised- and class-based divides and related marginalised social locations are reflected in inequities in access to and use of dementia services.

Background

The high prevalence of dementia among Caribbean populations is a concern for the Caribbean (Davis, Baboolal, Mc Rae, & Stewart, 2018; Molero, Pino-Ramirez, & Maestre, 2007) as well as for countries such as the United Kingdom (UK) (Adelman, Blanchard, Rait, Leavey, & Livingston, 2011) and United States of America (USA) (Mayeda, Glymour, Quesenberry, & Whitmer, 2016) where a high proportion of migrated Caribbean persons reside (Prince et al., 2013). According to 2011 UK census, 992,000 persons of foreign origin living in England and Wales identified themselves as Caribbean, making this group the second largest minority ethnic group (Adamson & Donovan, 2005; Adelman et al., 2011; ONS, 2012, 2015). Most of the Caribbean population that migrated to the UK during the post war period are reaching retirement age (Botsford, Clarke, & Gibb, 2012) and the older Caribbean population is estimated to grow to 3.8 million by 2051 (Lievesley, 2010).

The increasing number of Black, Asian and minority ethnic (BAME) people in the UK who are living with dementia (Prince et al., 2014) indicates the need for more community-centred and culturally-sensitive approaches. The 2015 UK policy paper titled *The Prime Minister's Challenge on Dementia 2020* presented a target of improving diagnosis rates for the BAME population (Parkin & Baker, 2016). Although this and related policy initiatives have likely contributed to addressing dementia care access and treatment in general in the UK (Pot & Petrea, 2013; WHO, 2012) there has been limited progress toward addressing the challenges and needs of BAME groups especially with a sensitivity to their intersectionality. By this we mean, an individual may experience disadvantage and discrimination along multiple dimensions (Burke, Owens, Serpe, & Thoits, 2003; Collins & Anderson, 1995) and not just according to mutually exclusive categories of social identity and location (e.g. race, social status, gender) (Sue, 2001). Current policy and practice are limited in such awareness and often fail to address cultural and social marginalisation that BAME persons face.

Studies exploring the role of marginalised cultural and social identities within dementia care systems are limited. This study focuses on the African-Caribbean diaspora. For the purpose of this study, the term 'African-Caribbean' refers to people of African ancestry who originate from the Caribbean countries (formerly known as 'The West Indies'), and other 'Caribbean Community and Common Market' (CARICOM) territories. With an attention to the positioning of African-Caribbean persons in their societies, this study explores their perceptions, influences upon making sense of dementia, experiences of care provisions, and their reports on the availability and accessibility of services. It examines key factors related to the experiences and preferences of African-Caribbean diaspora persons with dementia and their caregivers in gaining access to dementia-related health and social care information and services.

Scoping reviews are the most appropriate approach for this type of identification and mapping of available evidence (Munn et al., 2018). The scoping review was guided by the following questions: a) How do African-Caribbean people experience and conceptualise dementia? b) What formal and informal dementia services are available to and accessed by African-Caribbean people?

In this paper we first present findings from a scoping review of African-Caribbean persons' experiences, conceptualisations, and access and barriers to dementia services. Second, we compare and contrast the findings from the review and a consultancy exercise. Third, we discuss recommendations for policy, practice and future research.

Methods

The present study consisted of two phases. First a scoping review was conducted to identify and map the available evidence. Second key findings were explored in stakeholder consultations in Manchester (UK) and Jamaica to assist with further synthesis. The scoping review was guided by Arksey and O'Malley's (2005) framework and refined by the Joanna Briggs Institute's (JBI) methodology (Peters et al., 2017). This included identifying a research question, identifying relevant studies, selecting studies, extracting the data and collating, summarising and reporting the results. Consistent with these frameworks, we aimed to obtain an overview of the key themes in the existing research. It is important to note that risk of bias assessments and other assessments of methodological limitations is not conducted in scoping reviews (Arksey & O'Malley, 2005; Mays, Roberts, & Popay, 2001). Stakeholder consultations assisted with interpreting the results after the review was completed (Arksey & O'Malley, 2005; Daudt, van Mossel, & Scott, 2013; Levac, Colquhoun, & O'Brien, 2010). Stakeholder groups consisted of healthcare professionals working in dementia services, African-Caribbean people with dementia and their caregivers.

Searching for relevant literature

One of the authors (SB) conducted a search of electronic databases in March 2017. Another author (RL) repeated this search in May 2019. The search strategy was developed in consultation with the wider team and the systematic review service librarian (University of Manchester). SB and RL searched databases using the key terms 'dementia', 'Alzheimer', 'African-Caribbean' and their related terms (the detailed search strategy is available in supplementary table 1). Fourteen databases (AMED, Ovid Medline (R), PsycINFO, Embase, CINAHL, PubMed, NICE Evidence, Scopus, Open Grey, Web of Science, British Nursing Index, Applied Social Sciences and Abstracts (ASSIA), EBM reviews – Cochrane Central Register of Controlled Trials, EBM reviews – Cochrane Database of Systematic Reviews) were searched individually given their unique MeSH terms and thesaurus tools. SB and RL also applied lateral searching techniques such as cross-referencing search results across databases, utilising the 'cited by' tool in Google Scholar, searching 'related papers' and searching reference lists (Bunn et al., 2014).

Inclusion criteria were papers: originating from any country; written in any year; and written in English. Exclusion criteria were: epidemiologic and genetic studies; theses, books and other review papers; papers that did not present specific results for African-Caribbean participants; and papers lacking a focus on services for dementias.

Selecting literature

Electronic search results were exported to EndNote bibliographic software and duplicate citations were removed manually. SB and RL screened the search results in two stages. First, abstracts and titles were screened. Second, full text articles were retrieved to assess for inclusion. The list of articles considered for full text screening and reasons for exclusions are

available in supplementary table 2. Inter-library loans were sought for no access papers. Any disagreements in relation to the eligibility of articles were resolved at team meetings.

Data extraction

Informed by JBI's (Peters et al., 2017) methodology, key information from the studies were extracted under the following headings: author, year of publication, study design, study setting, study population and sample size, aims and key findings. The study characteristics are available in table 1. More descriptive data on conceptualisation of African-Caribbean peoples' experiences of dementia, service access and the meaning making process were charted through an in-depth analysis by two researchers (SB & RL) independently. To ensure the study rigour, conceptual data were discussed at team meetings and compared against the key findings. A table with a list of studies selected for full text screening and reasons for inclusion or exclusion (see supplementary table 2) was shared with the wider team for further ratification of any bias in study selection and data extraction.

Summarising & Expert consultation

Following Arksey and O'Malley's (2005) recommendations for thematic analysis, the team used an inductive approach to identify common themes (Braun & Clarke, 2006) and synthesise data. Key questions deduced from each of the themes helped to structure the stakeholder consultation meetings in Manchester (UK) and Jamaica with groups of people with dementia (Manchester n=18), carers (Manchester n=3, Jamaica n=3) and healthcare professionals (Manchester n=1, Jamaica n=4). Written feedback was collected from participants who were unable to attend the consultation meetings.

The papers extracted from a more recent search conducted in May 2019 are included in the overall reporting of the results. However, no new themes were generated from the four new studies included.

Results

The search yielded 2045 papers with 1,989 unique citations after manual removal of duplicates. On screening titles and abstracts a further 1654 papers were excluded, leaving 19 for analyses for the scoping review. The four papers identified through lateral search are included. Details of articles excluded from the review can be found in supplementary table 2. Figure 1 presents the study selection procedure.

Most articles were qualitative studies (73%, n = 14), three (16%) were quantitative papers and two (11%) were mixed methods papers. Fifteen studies (79%) were based in the UK, two studies (10%) in the USA, and the remaining two (10%) in the Caribbean. Twelve studies recruited caregivers, eight studies recruited people with dementia, five studies recruited staff and two studies recruited African-Caribbean general adult population. Table 1 presents detailed study characteristics of the included papers.

Thematic analysis

Using the Braun and Clarke (2006) framework to analysis that is described in table 2, the team identified the following four key themes: 1) Making sense of dementia; 2) Help-seeking –

Access and barriers; 3) Approaches to caring; and 4) Culturally sensitive services. The findings from the scoping review and stakeholder consultations are presented separately for each theme.

Theme 1: Making sense of dementia

The Scoping Review

A central aim of most studies (n = 10; 67%) was to explore how participants conceptualised dementia. Participants offered a range of explanations for dementia. Some explained dementia with reference to a biomedical model, i.e. impaired functioning or 'dying' of the brain (e.g. Adamson, 2001; Lawrence et al., 2011; Parveen, Peltier & Oyeboode, 2017). Dementia was also described as a normal part of ageing, somewhat expected, influenced by lifestyle, life events and medications for co-morbid conditions (Berwald et al., 2016; Botsford et al., 2012; Cheston et al., 2017; Lawrence, Samsi, Banerjee, Morgan, & Murray, 2011; Mukadam, Cooper, Basit, & Livingston, 2011; Adamson, 2001). Some studies reported that participants felt there was insufficient information about dementia available to them in their community (e.g. Moreland, 2001; Moreland, 2003; Parveen, Peltier & Oyeboode, 2016). Participants in studies also indicated that a lack of understanding about dementia contributed to their anxiety about the future (Lawrence et al. 2011). One study (Tappen et al., 2011) found that African-Caribbean persons scored low on cognitive screening and that the results were closely associated with levels of education.

Studies presented misconceptions and/or culturally specific beliefs about dementia. In one study, participants attributed dementia to 'too much aluminium in the brain'. In another, participants reported perceiving dementia as a 'white person's illness' i.e. unheard of in elders in the Caribbean and only becoming a problem following their migration to the UK. In some studies, participants explained dementia with reference to 'spirits' (All-Parliamentary Group on Dementia, 2013; Berwald, Roche, Adelman, Mukadam, & Livingston, 2016; Cheston et al., 2017). Dementia was described using stigmatising language such as 'madness' and 'mental' (Cheston et al., 2017; Lawrence et al., 2011; Moreland, 2001).

The data in the papers from which this theme was derived did not explicitly conclude that participants' gender or their age influenced their perceptions. A limited number of studies reported education/ professional background/ social class for participants according to ethnic group membership.

The Consultancy Exercise

The UK consultation with persons living with dementia echoed the review finding of persons having a limited understanding of dementia, its causes, and how to help someone with the condition. Some persons living with dementia described dementia as a normal and expected part of ageing.

Person living with dementia (UK): "There's no cure as far as I'm concerned but as you get older in your mind it change".

In both the UK and in Jamaica, in general the consultations with the informal carers offered conceptualisations of dementia that were consistent with review findings. They defined

dementia as a decline in brain function and as a long-term illness with no cure. They noted that dementia might be a result of physical inactivity and a lack of cognitive stimulation. They also noted that life stressors, trauma and drastic changes in lifestyle could be potential causes.

A few female carers in Jamaica expressed that because of multiple caregiving roles they assume, women are less likely to have time for self-care, and that this in turn increased the risks of developing dementia.

While not communicated in the consultations with UK based informal carers, in Jamaica a family caregiver expressed dementia as inevitable, suggesting that most people develop dementia in their lifetimes, that it is hereditary, and that nothing can be done to prevent it.

Informal carer (Jamaica): "Almost 80 to 90 percent of persons will get dementia, because everybody experiences some memory loss or symptoms of dementia...."

On discussion of review data which described dementia as a 'White person's illness', people living with dementia in the UK expressed that dementia is more prevalent in African-Caribbean people living in the UK as opposed to people living in the Caribbean. Some carers and health care professionals in the UK disagreed with this statement and suggested this view is probably due to lack of awareness about dementia in the Caribbean.

Person living with dementia (UK): "In my country that I'm from we had a lot of old people and they lived so long, ninety, a hundred and we never heard of their forgetfulness with dementia, we never hear that name! and they lived for long! And die with good sense you know..."

Consistent with this, a health care professional in Jamaica explained that there are limited resources and poor awareness of dementia in the Caribbean.

Some carers from the UK and Jamaica attributed dementia to fate or luck. Reflecting on the use of stigmatising language discussed in the reviewed studies, the health care professionals and carers in Jamaica and the UK acknowledged that the formal diagnosis of dementia was in itself stigmatising.

Health care professional (Jamaica): "We are far away from seeing dementia differently in Jamaica, not responding negatively such as saying 'that lady was so nice but went crazy.'"

Although the literature does not explicitly discuss identities within the socio-political environment, the data from the stakeholder consultations suggest gendered aspects to caregiving and that the external or societal environment plays a key role in conceptualisations of dementia.

Theme 2: Help seeking – Access and barriers

The Scoping Review

Thirteen (72%) studies discussed services that persons living with dementia and their carers attended, attitudes towards services and barriers. Participants identified General Practitioners (GPs)/family doctors as potential gatekeepers to memory clinics (Parveen, Peltier, & Oyeboode, 2017). Reservations about accessing GP service were often explained in relation to being worried about wasting the GP's time, costs, insufficient consultation time (Berwald et al., 2016; Cheston et al., 2017), and the GP's lack of awareness of cultural factors or adaptations needed for dementia services (Parveen et al., 2017; Roche, Mukadam, Adelman, & Livingston, 2018). Some male carers noted that previous unpleasant experiences at the GP and a lack of trust in services prevented them from seeking support (Berwald et al., 2016; Cheston et al., 2017). Some persons with dementia in the studies reviewed, particularly women living with dementia, noted that the diagnosis increased their fear of the future. The reviewed studies also reported that approaching health services evoked considerable fear of losing independence (Berwald et al., 2016), being taken away from family, being sectioned or 'locked up' (Baghirathan et al., 2018; Cheston et al., 2017), or being placed in a nursing home (Lawrence, Murray, Samsi, & Banerjee, 2008; Lawrence et al., 2011). However, a recent randomized control trial conducted in the UK suggested willingness among African-Caribbean older people – regardless of age and gender – to seek diagnosis if and when they faced memory problems. The study discussed organisational factors as potential contributory factors in delayed access to services (Roche et al., 2018).

Across multiple studies, participants reported that they avoided or delayed seeking help for memory problems because of negative experiences with services, stigma associated with mental health services and previous experiences of race-based discrimination (Berwald et al., 2016; Lawrence et al., 2008; Moreland, 2003; Mukadam et al., 2011; Parveen et al., 2017). Some people with dementia and carers described their encounters with health care professionals and statutory services as unhelpful. They described professionals being dismissive and prejudicial in their interactions (Berwald et al., 2016; Moreland, 2003). The Parveen et al. (2017) and the Brown and Murphy (2018) studies noted that on receiving a dementia diagnosis families withdrew from the wider community and kept the diagnosis a secret. This withdrawal had implications for persons living with dementia and their carers not accessing community groups for support.

Cheston et al. (2017) and Baghirathan et al. (2018) indicated that people living with dementia relied upon their family to make initial contact with services. Studies also noted included that family members: were unable to recognise the symptoms (Adamson, 2001; Brown & Murphy, 2018; Mukadam et al., 2011); adapted to dementia-related changes (Botsford et al., 2012); and that they waited until the crisis point to seek help. Another barrier the studies discussed was denial on the part of the person living with dementia (Berwald et al., 2016; Botsford et al., 2012; Mukadam et al., 2011). In some UK studies, older people and notably older women, reported that having no family in the UK affected their care and was linked to their delay in help-seeking (Berwald et al., 2016; Lawrence et al., 2011). The Tuerk and Sauer (2015) study indicated that people of African-Caribbean descent present to services at an advanced stage of dementia. The Baghirathan et al (2018) and Cheston et al (2017) studies highlighted that, compared to women, Caribbean men are less likely to engage with services and often feel isolated. In their investigation of caregiver burden in Trinidad Baboolal and colleagues (2018) highlighted a significant association between men as carers and the caregiver burden, with

their respondents noting that their health and wellbeing, financial and social life had been negatively impacted because of their role as carers.

On the topic of social care provisions, three UK-based studies discussed carers' concerns about the standard of care homes, overcrowding and the lack of culturally appropriate meals and daily activities (Brown & Murphy, 2018; Cheston et al., 2017; Lawrence et al., 2008). Carers reported that these factors made them consider care homes as a last resort. Regardless of their level of education, a majority of female carers in the Mukudam et al. (2011) study perceived external help as intrusive and preferred not to discuss their caring duties nor the diagnosis with anyone outside the family. The review findings also highlighted the need to make dementia specific and service related information culturally appropriate and easily available (Moreland, 2003).

The Consultancy Exercise

The stakeholder consultations in the UK with carers and health care professionals reiterated the review findings about GP services.

Stakeholders noted insufficient time for consultations and the GP's limited awareness of dementia services:

Informal carer (UK): "There was definitely something wrong with my mum, but the GP said he couldn't do test straight away due to time."

Health care professional (UK): "There is a Dementia Crisis Prevention Team who work within CMHT [Community Mental Health Team] but this support can only be accessed by referral from GP so relies on GP being aware of the pathway. Not all are."

In Jamaica, carers and health care professionals highlighted that some doctors were dismissive and were less likely to consider contextual information while making a diagnosis. This led the participants to question professionals' competencies.

Informal carer (Jamaica): "...I got a psychiatrist to come and assess her, but he was very reluctant to say that there was a mental problem. He said she seemed fine after the interview. I had told him what was happening before the interview. I feel he should have used the information I gave him to understand her behaviours, and not just the interview."

Echoing the review findings, people living with dementia and carers from both the UK and Jamaica discussed dementia as a condition for which there is no cure and as a normal part of ageing. Health care professionals noted their observations of a significant amount of fear and stigma associated with dementia. They noted families' inability to understand symptoms and recognise the early stages, and people with dementia withholding their symptoms from family. These data support the review findings about delayed recognition and acceptance of early symptoms and point to a potential role for programs and services for transforming attitudes.

Health care professional (Jamaica): "The culture makes the disease taboo..."

Informal carer (UK): "after seeing it then early diagnosis is important. My dad kept it from us then eventually broke down to us."

When they were presented with the review findings related to dementia care services, UK-based stakeholders identified funding cuts (APPG, 2013) to day care and befriending services as impacting their access to services.

Informal carer (UK): "...not with services cut. Used to have befriending, not anymore."

In addition UK-based stakeholders also confirmed lengthy diagnosis processes, GPs being overstretched, insufficient and inaccessible information regarding community services as some of the ongoing service-related challenges they face.

The consultancy group participants in Jamaica discussed other types of barriers that were also reflected in the literature. The barriers they focused on were around secrecy and not sharing information about a diagnosis or suspected case of such. They spoke about families and neighbours being over-protective, sympathetic and patronising. They noted that these attitudes and approaches were factors that influenced some carers to not share the diagnosis outside of the family and to not seek external support. Other carers noted that it was a part of their culture to keep the diagnosis within the family.

Informal carer (Jamaica): "I didn't want to say anything for a long time because of perceptions. I always heard...that dementia is worse than cancer. ...People's reactions were often very dramatic and so it made me not want to share it. ...People give you a sense of pity, that her life and my life is over, and that causes discomfort."

The stakeholders from Jamaica expressed that the communities are less empathetic towards people with mental illness. They discussed how a family's financial situation and social class restricted access and shaped their choices for support. They noted too that financial situation and social class played a role in understanding of dementia because their built-in privileges provided some people access to relevant information and resources while people in other groups were not even aware of those resources.

Informal carer, Male (Jamaica): "Information regarding dementia is really not that available."

Informal carer, Female (Jamaica): "...Certain classes who may have not had the education to know the symptoms and what [was] happening, what [was] serious and what [was] not."

Although some of the social factors discussed by groups in both locations were similar, none of the UK members presented social class or financial situation as a concern.

Theme 3: Approaches to caring

The Scoping Review

Caregiving was often framed as an important part of African-Caribbean culture. The majority of papers (n=10, 55%) examined aspects of confidentiality and privacy. Studies reported that family caregivers explained their caring role as a normal part of their relationships, their responsibilities, and their commitment towards family (Adamson & Donovan, 2005; Baboolal et al., 2018; Brown & Murphy, 2018; Mukadam et al., 2011). Mukundam et al. (2011) identified caregiving roles as more prevalent among the women compared to the men in their study, while noting that there had a majority of female participants. Carers in some studies explained that caring for parents was in some way reciprocating the care they received in childhood. They noted it was a virtue associated with being a “good Christian”. Other carers reported that being a family carer meant they had lost their independence and caring duties were to be prioritised over their needs (Lawrence et al., 2008). The caregivers report in the Brown and Murphy (2018) study noted that a lack of support from the wider family made caregiving more challenging. They also stated that financial constraints pressed them to take up employment, that that limited their ability to provide care, and that in turn led to them feeling remorseful. The spouse caregivers of people with dementia in Botsford et al. (2012) study indicated that they supported their partner with dementia in most aspects of everyday living and did not wish to burden the wider family with caring responsibilities. People with dementia suggested that a person with dementia should rely on care professionals rather than family for practical assistance (Lawrence et al., 2011). Participants in various studies reviewed noted that apart from family, third sector organizations and churches were significant sources of support (e.g. Parveen et al. 2017). Support from care professionals was discussed in some studies. Findings in studies suggested that residential homes were considered as a last resort because they were seen to have unsatisfactory standards of care (Brown & Murphy, 2018; Moreland, 2001, 2003).

The Consultancy Exercise

The stakeholder consultations in the UK and Jamaica affirmed review findings. One of the key findings that were supported was that caring responsibilities were largely shared within a family and that the wellbeing of people living with dementia depended upon this shared familial care.

Informal carer (UK): "They probably didn't have someone looking after them, that's why he got ill so quickly."

Some participants expressed particular satisfaction and pleasure with being able to look after their parents.

Informal carer (Jamaica): "I'm grateful I'm here to care for my mother. Because I feel like that's what I'm supposed to do."

Some carers thought that the lack of family involvement led to rapid deterioration of health. HCPs in Jamaica indicated, regardless of whether the family lived close by or at a greater distance (even outside the country), the family took responsibilities to organise care for their loved ones. This topic of long-distance caregiving or organising relevant support was not explicit in the reviewed literature on dementia and African-Caribbean persons.

The data from the stakeholder consultations in Jamaica echo the review findings on the role of informal caregivers, particularly their responsibilities and support. Stakeholders indicated

neighbours played an important role in caregiving for family members. The support system for family carers in Jamaica was described as inadequate. Stakeholders reported that this in turn contributed to carers feeling depressed, dealing with financial burden, and having to sacrifice their personal goals/ambitions. While discussing coping methods they suggested keeping busy with daily tasks.

Informal carer, Female (Jamaica): "I was depressed, but not wallowing and locking myself away. So I kept myself busy with practical needs. I feel there's nothing I can do to change what is happening, so I may as well just do what I can to take care of her...."

Some carer stakeholders also mentioned turning to alcohol as a coping mechanism.

Although the reviewed literature did not explicitly discuss women being better suited for caring roles than men, during consultations stakeholders indicated that women were often regarded as better suited to caring roles compared to men.

Stakeholders in both the UK and Jamaica confirmed review findings about support services, noting that churches and third sector organisations were important parts of their social life and sources of information. Stakeholders also reiterated review findings about professionals' lack of understanding and sensitivity to the needs of people living with dementia and their failure to provide dementia friendly holistic care.

Theme 4: Culturally sensitive services

The Scoping Review

Seven studies (47%) discussed the cultural needs of the African-Caribbean population within dementia services. People with dementia and carers in these studies emphasised the importance of seeking support from services that are respectful of cultural needs (APPG, 2013; Cheston et al., 2017; Parveen et al., 2017). However, it was also noted that these services were sometimes harder to access and more expensive. Participants also reported that they sought help from third sector organisations and local day centres. Churches were a particularly important source of support noted in some studies (Adamson & Donovan, 2005; Parveen et al., 2017). Studies described the benefits of having social groups/ dementia cafés and service providers with similar cultural background involved in delivering frontline care (APPG, 2013; Baghirathan et al., 2018; Cheston et al., 2017; Parveen et al., 2017). For example, in one study a participant described African-Caribbean people's reluctance to attend memory cafés noting that they do not want to 'stand out' and would prefer to share their experiences with people from a shared cultural background (Baghirathan et al., 2018; Cheston et al., 2017). In one paper, carers, persons living with dementia, and service providers suggested that it is important that services provide culturally appropriate cuisine (APPG, 2013). Language was also an important cultural consideration. Studies indicated that Standard English was not the preferred language for African-Caribbean persons living with dementia. In Cheston's (2017) study, Standard English was described as a 'performance language' for older generations. One study noted that there is no word for dementia in different Caribbean dialects or patois (Moreland, 2001) and that this may be linked to the difficulty that some African-Caribbean people have with conceptualising 'dementia'. Finally, the study also suggested that healthcare professionals were not always culturally competent,

that they lacked confidence, and that some of the assessment tools were not fit for purpose for use with African-Caribbean persons living with dementia.

The Consultancy Exercise

Consistent with the scoping review findings, all stakeholder groups in the UK emphasised the need for dementia services to be culturally sensitive. For example, a carer reported that providing opportunities for people to reminisce with others from a shared cultural background, acknowledging the importance of religion, and providing African-Caribbean food during the meetings are factors that contribute to fostering a conducive environment for socialising and engagement with services.

Informal carer (UK): "With some people the chance to talk about 'home' and reminisce about growing up and coming to England is beneficial. Preparation of home cooked food and taking a general interest in that person is vital."

Health care professional (UK): "The majority of people here are from the West Indies, but they are from different part. They're not all from the same place so it's good. And they interact and they talk about where they're from and so on so that's good as well."

Carers from the UK provided more socio-political context-sensitive ideas about why the shared cultural background is important to African-Caribbean people living with dementia. Noting that people living with dementia can often 'go back thirty or forty years', they pointed out that this means that they talk about their early memories growing up in the Caribbean and moving to England during the Windrush era. They spoke about this being a life event that is difficult to communicate with people who have not shared this experience but a context that is necessary to understand the African-Caribbean person living with dementia in the UK.

Informal carer (UK): "They'll be living in Jamaica, and when they first come over and they'll be talking about what happened when they first come or whatever, but they could never talk about that with a white person because when they first come, what was it 'no Blacks, no Irish, no dogs'? You know what I mean?"

Two UK stakeholders (one HCP and one informal carer) reported times where a person living with dementia did not want to attend a group activity because there were no other Caribbean people. One carer hypothesized that this might be because the person living with dementia would feel 'singled out'.

Health care professional (UK): "One family said that they didn't want their dad going to a day service because there were too many women and no other African-Caribbean people there."

In response to the review findings about services in residential care settings, the informal carers and HCPs from Jamaica stated that the activities at nursing homes were not mentally stimulating and engaging.

Health care professional (Jamaica): "I have been to nursing homes, and they [the persons living with dementia] do nothing but sit and stare at each other with the TV

on in the background. In the States (USA) they were always stimulated. And I found they did not lose language as quickly.”

While funding was not extensively examined in the reviewed literature, dementia services funding and funding cuts was discussed in the UK stakeholder consultations. Some carers in the UK highlighted ways in which the funding cuts affected their relative’s wellbeing. They noted that the lack of funding meant the closure of pick up and drop off services to the group activities and that it increased reliance on unpaid volunteers. Some carers also mentioned dementia choirs as an essential service for persons living with dementia as it took the focus away from dementia, removed stigma, and helped the person living with dementia be a member of a group, and to engage in community activities. The little attention given to the topic of funding when compared to its prominence as a topic in the stakeholder consultations in the UK suggests that funding is an area for future research. It is worth considering how the political and economic landscape impact access to services, and more specifically, access for specific social groups. Such access is crucial to improving the quality of life for people with dementia.

Discussion

The reviewed studies discuss the meaning-making process of dementia, drawing on the perspectives and experiences of people living with dementia, informal carers, and healthcare professionals. These studies offer limited insight into the interactions of African-Caribbean persons’ multiple identities and how these position them within their sociocultural contexts. Multiple Identities in this study refers to how individuals define their individuality by inferring to their self-knowledge, roles and position within the culture, family, background, education, skills, economy, class, ethnicity, race and situational contexts (Ramarajan, 2014). Although some of the studies address gender, class, and ethnicity as characteristics that influence dementia conceptualisation and service access (Adamson, 2001; APPG, 2013; Baghirathan et al., 2018; Botsford et al., 2012; Brown & Murphy, 2018; Cheston et al., 2017; Lawrence et al., 2011), they do not adequately discuss the implications of these intersecting social statuses for improving African-Caribbean peoples’ experiences with dementia care. It is crucial to understand how people navigate and internalise status, class, ethnicity, roles and physical space in everyday life and the implications for conceptualising and addressing inequalities in dementia service availability and access. Furthermore, implementation of person-centred dementia care requires that the multiple marginalised positions they have experienced and still have to navigate is acknowledged and addressed in sensitive and effective ways. This involves going beyond the narrowly conceptualised influence of an often minimally defined ethnic ‘culture’ (Zubair & Norris, 2015), and considering instead how the varied intersections of ‘race’/ racialization, ethnicity, social class, and gender may have an impact on the ensuing healthcare-related inequalities (Tang, Browne, Mussell, Smye, & Rodney, 2015) for African-Caribbean populations in different national contexts.

Recognising networks of social and situational identities can inform a better understanding of variations in perceptions observed in the reviewed studies. For example, the studies that discussed participants’ descriptions of dementia as ‘White person’s illness’ and as a normal process of ageing, (APPG, 2013; Berwald et al., 2016; Cheston et al., 2017) considered African-Caribbean peoples’ ethnic identity. It might be useful to explore instead an analysis of intersecting influences of social class and varied levels of education of this ethnic group that

is presumed to be homogenous but is quite heterogeneous (country of origin, profession, education attained, and gender). The stakeholder consultations in Jamaica and the UK indicated high levels of awareness regarding the risk factors for dementia. They also pointed to the ways in which stigma (Cheston et al., 2017; Moreland, 2003; Mukadam et al., 2011) and socio economic disparities (APPG, 2013; Brown & Murphy, 2018) may be barriers to service access. Thus, membership of a lower status and marginalised social position is likely to put African-Caribbean persons – whether living in the UK, USA or in a Caribbean country – at a greater disadvantage in terms of engagement with dementia services.

The reviewed studies which presented research evidence mainly from the UK and USA contexts, outlined a number of barriers to help-seeking. These factors included both general issues and those presumed to be culture-specific. Key barriers included: stigma; denial and non-recognition of symptoms; perceptions of external help as intrusive; fear of being institutionalized or locked up; specific religious beliefs; professionals' lack of cultural awareness; and professionals' dismissive attitudes (Adamson, 2001; Berwald et al., 2016; Botsford et al., 2012; Brown & Murphy, 2018; Cheston et al., 2017; Lawrence et al., 2011; Moreland, 2003; Mukadam et al., 2011; Parveen et al., 2017; Tappen, Gibson, & Williams, 2011; Truswell, 2016; Tuerk & Sauer, 2015).

A key socio-cultural barrier noted was African-Caribbean persons' negative experiences of racism with services as well as in the wider UK and USA society (Mukadam et al., 2011). Although the existing literature addressed barriers to dementia service access under the broader explanation of ethnic cultural differences, it engaged little with the discourse of identities. The significance of specific identities, process of internalisation, social locations and positioning as racialised and minority ethnic populations in the UK and USA contexts must be taken into consideration in the design and implementation of culturally-appropriate services. They are important contributory factors likely to result in the marginalised position of the African-Caribbean population in those contexts and their unequal access to services.

Much of the research literature from the UK and USA did not sufficiently consider the significance of social class locations in conceptualising dementia and service access. The Jamaica stakeholder consultations highlighted social class as an important barrier to service access for those in that context, which has a health and social care delivery system different from that of the UK and the USA.

Some literature in the UK (APPG, 2013; Brown & Murphy, 2018) and the stakeholder consultations pointed to the impact of socioeconomic status upon people's choices. Having limited financial resources and being a member of a specific minority ethnic group placed people in a marginalised physical and social space. Additionally, cut back on government's funding provisions to support continuation of innovative services for minority ethnic populations in the UK meant discontinuity, chaos and a significant impact on the lives of these people living with dementia and their carers.

Limitations and recommendations for future studies

There is a lack of research evidence on dementia relating to Caribbean populations in North America and the Caribbean region in particular. It is therefore difficult to examine national policies, cultures and resources and to make comparisons in these areas across countries.

The small but growing body of UK-based research literature has predominantly focussed on African-Caribbean ethnicity as an important factor influencing their understandings of dementia and access to dementia services. Our comparative focus involving participants living in the Caribbean suggests that in order to provide culturally appropriate access and services it may be useful to consider ethnicity as a context for exploring multiple intersecting factors that impact service access. Our findings indicate that barriers to service access in the UK are linked with experiences of racial, culture-based and socioeconomic exclusions; in the Jamaican context barriers appear to be informed by social class and financial resources. The role of inequalities, including systemic inequalities, is important in both national contexts. This understanding is reinforced for us through a comparative focus that considers race, ethnicity, class, gender, economy, education, profession, location, politics and social space as processes influencing identities in a given society and across various national contexts. Future comparative work on dementia care with and for African-Caribbean populations can further explore the complex and interlinked processes that disadvantage the diverse members of this population in terms of a lack of appropriate access to dementia services. Future studies can inform improvements to dementia care availability and access for this population by considering in their designs, implementations, and output the socio-cultural, political-economical processes that lead to marginalisation in dementia care-systems. They can also focus on interventions/ strategies that address such processes.

Some of the other limitations of this study include the lack of people with dementia at consultation events in Jamaica and limited feedback from healthcare professionals at the UK-based consultation events. The limited number of key stakeholder participants indicates that more customized community engagement approaches and strategies are needed to ensure that the voices of members of this population are included in the development and design of services and programmes that target them.

Implications for practice and policy

The review data found that there was not a unanimous agreement among participants that caring was a manageable family duty; instead they reported that it was also an obligation that presented a considerable burden on families (Adamson & Donovan, 2005; Baboolal et al., 2018; Botsford et al., 2012; Brown & Murphy, 2018; Mukadam et al., 2011; Parveen et al., 2017). There is a stereotype that members of African-Caribbean communities perceive external professional help as undesirable. However, these review findings suggest that external or professional help may in fact be appreciated. The review findings indicated that what is resisted is services and help where African-Caribbean people feel discriminated against or do not experience culturally sensitive and appropriate service provision.

The issues of access and acceptability of dementia services, whether in the UK or in Jamaica are complex and go beyond a simple, singular, issue of cultural difference. This requires cultural sensitivity and improving access to quality mainstream person-centred dementia services. Some of the important aspects of quality improvement suggested in the overall findings involve better service integration, clearer referral pathways for dementia diagnosis and care, and appropriate education and training of healthcare professionals in relation to culturally informed person-centred dementia care (Manthorpe & Samsi, 2016).

Although NHS England's transformation framework for the dementia pathway (Department of Health, 2015) sets out standards for 'supporting well', 'living well and dying well with

dementia', its application and implementation varies across regions. For example, the findings indicated GP services in some locations are perceived as unapproachable and not proactive in signposting families to dementia services, and that the lack of culturally appropriate assessment tools and outcome measures make diagnosis and intervention challenging. While the framework for the dementia pathway is robust, there is a gap in implementation. Understanding the impact of multiple marginalised identities in dementia care availability and access can influence diagnosis rates, service access, and culturally adapted implementation of proposed standards under the framework, particularly for BAME communities.

Ethnic identities and the ways they interact with other social identities are associated with multiple marginalizations. To address systemic inequalities in dementia care these intersections need to be considered at the level of both local services and at a national level (i.e. in terms of policy and clinical practice). Findings from this study suggest that uptake of and participation in community-based dementia services are determined by feelings of belonging, inclusion, similarity, approachability, and trust –not necessarily by expert knowledge of dementia as a condition. This points to the need for greater cultural sensitivity in community-based and charity-led services (dementia cafés, singing groups, book clubs, activity groups). There is currently little evidence to indicate how the UK's national policies and practice guidelines address wider inequalities around 'race', racism, and racialized identities and exclusions. Special attention needs to be paid to the UK's national policies to avoid placing certain racialised and minority groups in further marginalised positions and thereby being counter-productive in terms of building trust in the dominant healthcare services. Similarly, as social class appears to be a significant barrier to equitable service access within the Jamaican context, policy and practice in this context need to be responsive to wider systemic inequalities around social class and financial status. Services in Jamaica may also benefit from more public education about dementia and increasing the friendliness, approachability and person-centeredness of dementia-specific and general healthcare services.

Conclusion

This study enhances the current literature by bringing to forefront the complex interaction of socio-cultural processes that marginalise African-Caribbean persons in and across various national settings. The study produces insight into the diversity of dementia experiences within the assumed homogeneity of the African-Caribbean group even within the Jamaican cultural context. Current policy and practice must address the inequalities linked with marginalised social locations and more specifically the powerful influence of the prevalent racialised and classed social divides and exclusions on access to information about dementia and dementia services.

Funding

We thank Manchester Institute for Collaborative Research in Ageing (MICRA) for funding this review project.

Acknowledgments

We thank Mrs. Tiffany Palmer and Mrs. Josie Reynolds for their assistance with stakeholder consultations in Jamaica. We specially thank the persons living with dementia, the informal

carers, and the healthcare professionals who participated in the consultation sessions and offered valuable insights.

References

- Adamson, J. (2001). Awareness and understanding of dementia in African/Caribbean and South Asian families. *Health & Social Care in the Community*, 9(6), 391-396.
- Adamson, J., & Donovan, J. (2005). 'Normal disruption': South Asian and African/Caribbean relatives caring for an older family member in the UK. *Social Science & Medicine*, 60(1), 37-48. doi:10.1016/j.socscimed.2004.05.002
- Adelman, S., Blanchard, M., Rait, G., Leavey, G., & Livingston, G. (2011). Prevalence of dementia in African-Caribbean compared with UK-born White older people: two-stage cross-sectional study. *The British Journal of Psychiatry*, 199(2), 119-125. doi:<http://dx.doi.org/10.1192/bjp.bp.110.086405>
- APPG. (2013). *Dementia does not discriminate - The experiences of black, Asian and minority ethnic communities*. Retrieved from https://www.alzheimers.org.uk/download/downloads/id/1857/appg_2013_bame_report.pdf
- Arksey, H., & O'Malley, L. (2005). Scoping studies: towards a methodological framework. *International journal of social research methodology*, 8(1), 19-32.
- Baboolal, N., Davis, G., Stewart, R., Ramesar, J., & McRae, A. (2018). Comparisons between different elements of reported burden and common mental disorder in caregivers of ethnically diverse people with dementia in Trinidad. *PLoS One*, 13(7), e0201165. doi:10.1371/journal.pone.0201165
- Baghirathan, S., Cheston, R., Hui, R., Chacon, A., Shears, P., & Currie, K. (2018). A grounded theory analysis of the experiences of carers for people living with dementia from three BAME communities: Balancing the need for support against fears of being diminished. *Dementia*, 1471301218804714.
- Berwald, S., Roche, M., Adelman, S., Mukadam, N., & Livingston, G. (2016). Black African and Caribbean British Communities' Perceptions of Memory Problems: "We Don't Do Dementia.". *PLoS One*, 11(4), e0151878. doi:10.1371/journal.pone.0151878
- Botsford, J., Clarke, C. L., & Gibb, C. E. (2012). Dementia and relationships: experiences of partners in minority ethnic communities. *Journal of Advanced Nursing*, 68(10), 2207-2217. doi:10.1111/j.1365-2648.2011.05905.x
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, 3(2), 77-101.
- Brown, C. R., & Murphy, M. M. (2018). Barriers to informal caregiving of persons living with dementia in Barbados: A phenomenological inquiry. *West Indian Medical Journal*, 67(3), 206-211. doi:10.7727/wimj.2017.142
- Bunn, F., Burn, A.-M., Goodman, C., Rait, G., Norton, S., Robinson, L., . . . Brayne, C. (2014). Comorbidity and dementia: a scoping review of the literature. *BMC medicine*, 12(1), 192.
- Burke, P. J., Owens, T. J., Serpe, R. T., & Thoits, P. A. (2003). *Advances in identity theory and research*: Springer.
- Cheston, R., Baghirathan, S., Hui, R., Shears, P., Chacun, A., & Currie, K. (2017). *The dementia experiences of people from Caribbean, Chinese and South Asian communities in Bristol*. Retrieved from
- Collins, P. H., & Anderson, M. L. (1995). Race, class and gender. *Belmont, Calif.: Wadsworth*.
- Daudt, H. M., van Mossel, C., & Scott, S. J. (2013). Enhancing the scoping study methodology: a large, inter-professional team's experience with Arksey and O'Malley's framework. *BMC medical research methodology*, 13(1), 48.

- Davis, G., Baboolal, N., Mc Rae, A., & Stewart, R. (2018). Dementia prevalence in a population at high vascular risk: the Trinidad national survey of ageing and cognition. *BMJ Open*, 8(2). doi:10.1136/bmjopen-2017-018288
- Department of Health. (2015). *Prime Minister's challenge on dementia 2020*. Retrieved from <https://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020>
- Gridley, K., Aspinall, F., Parker, G., Weatherly, H., Faria, R., and, F. L., & Berg, B. v. d. (2019). Specialist nursing support for unpaid carers of people with dementia : a mixed-methods feasibility study. *NIHR Journals Library – Health Services and Delivery Research*.
- Lawrence, V., Murray, J., Samsi, K., & Banerjee, S. (2008). Attitudes and support needs of Black Caribbean, south Asian and White British carers of people with dementia in the UK. *British Journal of Psychiatry*, 193(3), 240-246.
- Lawrence, V., Samsi, K., Banerjee, S., Morgan, C., & Murray, J. (2011). Threat to Valued Elements of Life: The Experience of Dementia Across Three Ethnic Groups. *Gerontologist*, 51(1), 39-50. doi:10.1093/geront/gnq073
- Levac, D., Colquhoun, H., & O'Brien, K. K. (2010). Scoping studies: advancing the methodology. *Implementation Science*, 5(1), 69.
- LGA. (2018). Dementia support guide for councils.
- Lievesley, N. (2010). The future ageing of the ethnic minority population of England and Wales. *London: Runnymede and the Centre for Policy on Ageing*.
- Manthorpe, J., & Samsi, K. (2016). Person-centered dementia care: current perspectives. *Clinical Interventions in Aging*, 11, 1733-1740. doi:10.2147/CIA.S104618
- Mayeda, E. R., Glymour, M. M., Quesenberry, C. P., & Whitmer, R. A. (2016). Inequalities in dementia incidence between six racial and ethnic groups over 14 years. *Alzheimer's & dementia : the journal of the Alzheimer's Association*, 12(3), 216-224. doi:10.1016/j.jalz.2015.12.007
- Mays, N., Roberts, E., & Popay, J. (2001). Synthesising research evidence. *Studying the organisation and delivery of health services: Research methods*, 188-220.
- Molero, A. E., Pino-Ramirez, G., & Maestre, G. E. (2007). High prevalence of dementia in a Caribbean population. *Neuroepidemiology*, 29(1-2), 107-112. doi:10.1159/000109824
- Moreland, N. (2001). Twice a child: dementia care for African-Caribbean and Asian older people in Wolverhampton. *London: Dementia UK*.
- Moreland, N. (2003). Twice a child II: service development for dementia care for African-Caribbean and Asian older people in Wolverhampton. *London: Dementia UK*.
- Mukadam, N., Cooper, C., Basit, B., & Livingston, G. (2011). Why do ethnic elders present later to UK dementia services? A qualitative study. *International psychogeriatrics*, 23(7), 1070-1077.
- Munn, Z., Peters, M. D. J., Stern, C., Tufanaru, C., McArthur, A., & Aromataris, E. (2018). Systematic review or scoping review? Guidance for authors when choosing between a systematic or scoping review approach. *BMC medical research methodology*, 18(1), 143. doi:10.1186/s12874-018-0611-x
- ONS. (2012, 17th December 2012). 2011 Census: Population Estimates for the United Kingdom, March 2011. Retrieved from <https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/bulletins/2011censuspopulationestimatesfortheunitedkingdom/2012-12-17>
- ONS. (2015). *2011 Census Analysis: Ethnicity and Religion of the Non-UK Born Population in England and Wales*. Retrieved from http://webarchive.nationalarchives.gov.uk/20160106070721/http://www.ons.gov.uk/ons/dcp171776_407038.pdf
- Parkin, E., & Baker, C. (2016). Dementia: policy, services and statistics. Retrieved from <http://researchbriefings.files.parliament.uk/documents/SN07007/SN07007.pdf>.

- Parveen, S., Peltier, C., & Oyeboode, J. R. (2017). Perceptions of dementia and use of services in minority ethnic communities: a scoping exercise. *Health and Social Care in the Community*, 25(2), 734-742. doi:10.1111/hsc.12363
- Peters, M., Godfrey, C., McInerney, P., Baldini Soares, C., Khalil, H., & Parker, D. (2017). Chapter 11: Scoping Reviews Joanna Briggs Institute Reviewer's Manual: Joanna Briggs Institute.
- Peterson, J., Pearce, P. F., Ferguson, L. A., & Langford, C. A. (2017). Understanding scoping reviews: Definition, purpose, and process. *Journal of the American Association of Nurse Practitioners*, 29(1), 12-16. doi:10.1002/2327-6924.12380
- Pot, A., & Petrea, I. (2013). Improving dementia care worldwide. Ideas and advise on developing and implementing a national dementia plan.
- Prince, M., Bryce, R., Albanese, E., Wimo, A., Ribeiro, W., & Ferri, C. P. (2013). The global prevalence of dementia: a systematic review and metaanalysis. *Alzheimer's & Dementia*, 9(1), 63-75. e62.
- Prince, M., Knapp, M., Guerchet, M., McCrone, P., Prina, M., Comas-Herrera, A., . . . King, D. (2014). Dementia UK: update. *Alzheimer's Society, London*.
- Ramarajan, L. (2014). Past, present and future research on multiple identities: Toward an intrapersonal network approach. *The Academy of Management Annals*, 8(1), 589-659.
- Roche, M., Mukadam, N., Adelman, S., & Livingston, G. (2018). The IDEM-Care Study Improving Dementia Care in Black African and Caribbean Groups: A feasibility cluster randomised controlled trial. *International Journal of Geriatric Psychiatry*, 33(8), 1048-1056. doi:10.1002/gps.4891
- Sue, D. W. (2001). Multidimensional Facets of Cultural Competence. *The Counseling Psychologist*, 29(6), 790-821. doi:10.1177/0011000001296002
- Tang, S. Y., Browne, A. J., Mussell, B., Smye, V. L., & Rodney, P. (2015). 'Underclassism' and access to healthcare in urban centres. *Sociology of Health & Illness*, 37(5), 698-714. doi:10.1111/1467-9566.12236
- Tappen, R. M., Gibson, S. E., & Williams, C. L. (2011). Explanations of AD in ethnic minority participants undergoing cognitive screening. *Am J Alzheimers Dis Other Demen*, 26(4), 334-339. doi:10.1177/1533317511412047
- The Mental Health Foundation and Housing & Care. (2018). An evaluation of the Standing Together project. *Mental Health Foundation*.
- Truswell, D. (2016). Communities can't be left to 'look after their own'. *Journal of Dementia Care*, 24(6), 26-28.
- Tuerk, R., & Sauer, J. (2015). Dementia in a Black and minority ethnic population: characteristics of presentation to an inner London memory service. *BJPsych Bulletin*, 39(4), 162-166. doi:10.1192/pb.bp.114.047753
- WHO. (2012). *Dementia: a public health priority*. Retrieved from http://apps.who.int/iris/bitstream/10665/75263/1/9789241564458_eng.pdf?ua=1
- Zubair, M., & Norris, M. (2015). Perspectives on ageing, later life and ethnicity: ageing research in ethnic minority contexts. *Ageing and Society*, 35(5), 897-916. doi:10.1017/S0144686X14001536

Figure 1: Study selection

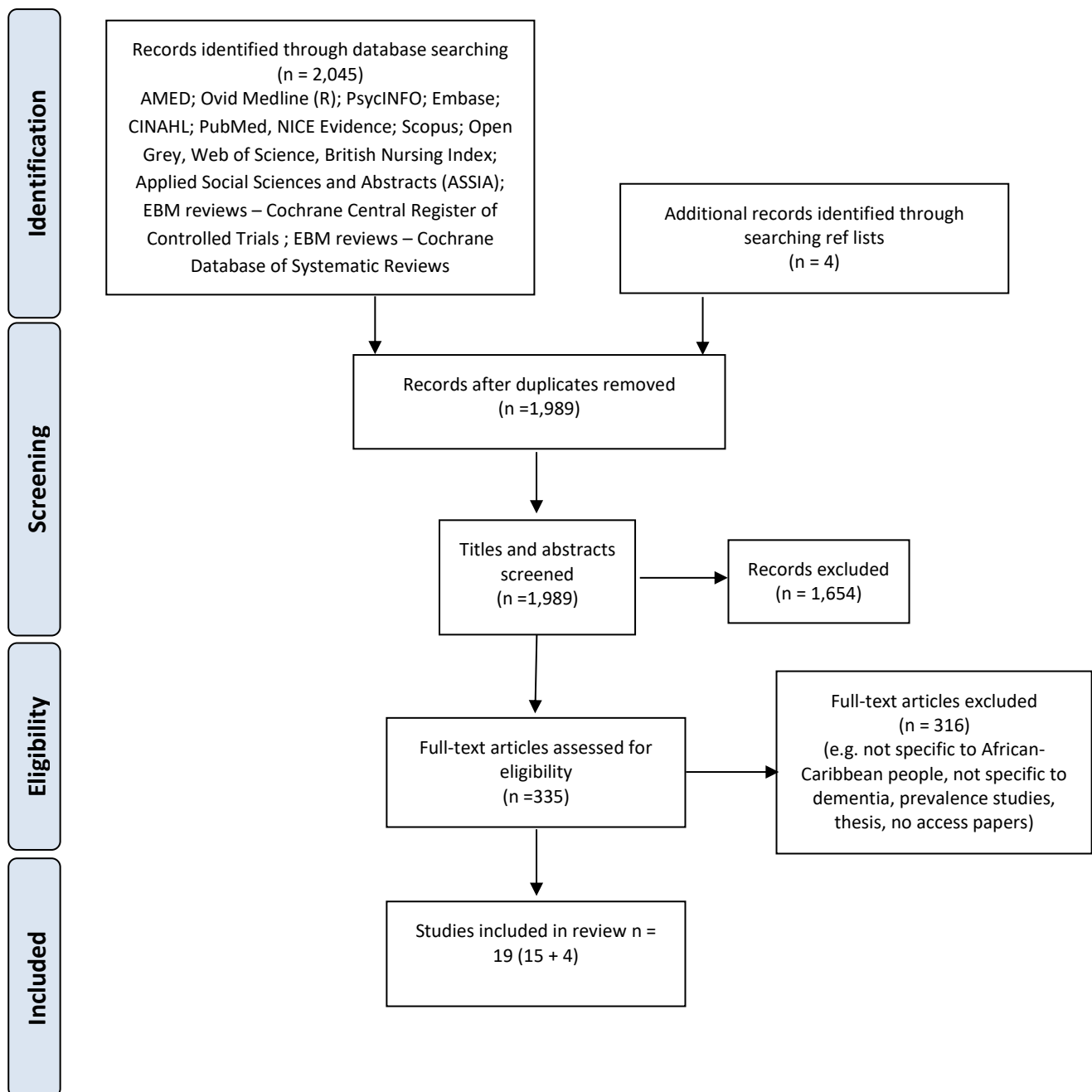


Table 1: Study characteristics

Author (year)	Study design	Study setting	Sample	Aims	Key findings
Adamson (2001)	Qualitative	UK (England)	Total participants: 30 (carers) African-Caribbean: 18 (Female-15, Male -3; spouse-7, daughter-9, son -1, niece-1); South Asian: 12	To explore African-Caribbean and South Asian carers' understanding of dementia and experiences of caring for their relative	African-Caribbean carers had some understanding of their relative's dementia but in some cases awareness of dementia was only acquired after their relative's formal diagnosis, which often lead to delays in help-seeking.
Adamson & Donovan (2005)	Qualitative	UK (England)	Total participants: 36 (carers) African-Caribbean: 21 South Asian: 15	To develop an understanding of African-Caribbean and South Asian people's experiences of informal caring of an older relative with dementia	Caring was described as 'normal disruption' and generally explained within a cultural framework whereby caring was viewed a pivotal part of family duty, moral obligation, and one's religious values. Most often, caring responsibilities belonged to a daughter with whom the PwD had previously shared a house with before they required care.
Baboolal et al., (2018)	Quantitative	The Caribbean (Trinidad and Tobago)	Total participants: 75 PwD- carer dyads PwD ethnic groups: African: 36; East Indian: 13; Other: 26	To examine potential cultural differences in caregiver burden in different ethnic groups in Trinidad and Tobago. The Zarit Burden Interview [ZBI] was used to measure caregiver burden and the General Health	Mean ZBI (burden) score was higher in carers of PwDs belonging to the "Other" ethnicity group (27.8) compared to carers of PwDs of African (20.7) and East Indian (18.2) descent. In summary, caregiver burden was significantly higher in male carers belonging to minority groups (In Trinidad and Tobago this would refer to individuals who are <i>not</i> of African or East Indian background). Additionally,

				Questionnaire [GHQ] assessed psychiatric morbidity.	carers who reported greater burden had increased GHQ scores.
Baghirathan et al (2018)	Qualitative	UK (England)	Total of 76 participants (carers & staff from voluntary organisations) -47 people from different South Asian communities (Muslim, Hindu and Sikh), 31 people from the Chinese community and 25 people from African Caribbean community.	To generate a grounded theory guided by the following questions: what experiences do people from three different BAME communities who provide care for people living with dementia in Bristol have of dementia-specific care? Secondly, why do they “think people might be reluctant to access dementia care services?	Caribbean men expressed visiting the doctor to discuss memory loss or other concerns was to risk being ‘locked up. For some Caribbean participants the isolation of being the only visible person from a BAME community within a service thereby risked their cultural needs being ignored or disregarded. Many informants described a wish to hide the vulnerabilities that arose from dementia for as long as possible. Participants reported greater reliance on BAME led voluntary organisations and churches.
Berwald et al. (2016)	Qualitative	UK (England)	Total participants: 50 (4 carers, 4 people being assessed for memory problems, 2 support workers, 40 members of the public); Black African: 28; African-Caribbean:14;Black	To determine potential obstacles encountered by Black and African-Caribbean people when seeking help for dementia	Participants demonstrated an inability to recognise early warning signs, for example attributing forgetfulness to the normal ageing process. Dementia was described as a ‘white persons illness’. Participants reported a reluctance to discuss problems due to concerns over time and privacy. It was also commonly reported that problems reached ‘crisis point’ before help was sought. Additionally, there was also a reluctance to seek help due to the

			British: 7;Indo-Caribbean: 1		fear of losing independence or becoming 'institutionalised'.
Botsford, Clarke & Gibb (2012)	Qualitative	UK (England)	Total participants: 13 (Female-6, Male-7; partners of people with dementia) African-Caribbean: 6 Greek Cypriot: 7	To examine the experiences of African-Caribbean and Greek Cypriot people in a relationship with a PwD	African-Caribbean participants tended to be more individual and couple-orientated. Participants reported that they initially adapted to the early warning signs exhibited by their partner, by attributing them to normal ageing and choosing not to seek help. In some cases, this meant that help was not sought after until problems reached crisis point. After acceptance of the dementia diagnosis, relationships followed a process of redefinition. This process included a dealing with the changes and developing coping strategies
Brown & Murphy (2018)	Qualitative	The Caribbean (Barbados)	Eight informal (family) care-givers of people living with dementia in Barbados	To explore the barriers of primary informal caregivers to caring for persons living with dementia (PLWDs) in Barbados	Four central themes were extracted from the interview data: imbalanced family dynamics, financial and time constraints, dissatisfaction with formal care services, and misunderstanding of complex symptomatology. Family dynamics addressed issues of limited support from other siblings or adult children in caring for PwD, balance the challenges of own families while caring for PwD.

Caregivers, whether employed or unemployed, admitted to not offering as much care as they would like and struggled financially.

Caregivers were concerned about overpopulation, and subsequent insufficiency and overmedication in formal care centres.

Limited/lack of recognition of symptoms at pre and post diagnosis stage that impacted PwD's behaviours were often the cause of conflicts and misunderstandings in relationships.

Cheston et al. (2017)	Qualitative	UK (England)	Total African-Caribbean participants: 10 (1 PwD, 8 family carers, one person concerned that they might have dementia).	To explore the understanding and experiences of dementia and services of three minority groups (African-Caribbean, Chinese & South Asian)	Participants reported services as oppressive and some people (particularly men) felt mistrustful of services for dementia. Participants voiced a need for culturally sensitive services that meet the needs of the African-Caribbean community. Most people had an awareness of the term 'dementia' but there were gaps in knowledge, for example viewing the condition as part of normal ageing. Some participants explained that caring for family 'until the very end' is an important part of their culture. People also explained that they avoided services because they were worried about the quality of care they would provide their relative with dementia.
-----------------------	-------------	--------------	--	---	--

Cohen, Hyland & Magai (1998)	Quantitative	USA (Brooklyn)	Total participants: 286 (PwD); African-American: 164; African-Caribbean: 54; Caucasian: 68	To assess whether any interracial and intra-racial differences are present in demographic variables, symptomatology and treatment of PwD living in a nursing home	The African-Caribbean group data was analysed to examine intra-racial differences. There were no significant differences in the clinical and social variables of the African-Caribbean and African-American groups. The only significant difference between groups was in marital status; that is, U.S.-born African Americans were more likely to have been widowed whereas African Caribbeans were more likely to have been separated/divorced or never have been married. This finding was trivial because the two groups had nearly equal rates of being unmarried and living alone at the time of institutionalization. While there are many cultural differences between U.S.-born African Americans and African Caribbeans, it is likely that the increased standardization of nursing home admission criteria along with their socioeconomic and racial similarities may have attenuated any potential differences.
House of Commons All-Party Parliamentary Group on Dementia report (2013)	Qualitative	UK (England)	Total participants: NR (PwD, carers and service providers) Irish, Indian, Pakistani, African-Caribbean and Chinese	To determine understanding of dementia, service requirements and experiences faced by carers and people living with dementia within the BAME community	African-Caribbean participants had some misconceptions about dementia for example attributing it to 'spirits' or conceptualising it as 'a white person's illness' and suggested that dementia has only become apparent since Caribbean people moved to the UK. People also voiced a concern about a lack of culturally sensitive services and explained that people with dementia often become

socially isolated because people within their social network do not know how to deal with the condition

Lawrence et al. (2008)	Qualitative	UK (England)	Total participants: 32 (carers) African-Caribbean: 10 South Asian: 10 White British: 12	To assess the needs of African-Caribbean, South Asian and White British informal carers, and their experiences of caring for a PwD	Carers were dichotomised into two distinct groups, those who viewed caring as natural and honourable (traditional) and those who viewed caregiving as unnatural and disruptive (non-traditional). Some African-Caribbean participants described caring as virtuous and an important part of their cultural identity, but others felt trapped, stressed, and thought of caregiving as a threat to their independence.
Lawrence et al. (2011)	Qualitative	UK (England)	Total participants: 30 (PwD) African-Caribbean: 11 (Female-8, Male-3; single-1, married-3, divorced-2, widowed-5; living alone-4, with spouse-1, with family-4, sheltered accommodation-2); South Asian: 9; White British: 10	To explore the experiences African-Caribbean, South Asian and White British PwD	African-Caribbean PwD commonly described dementia using stigmatising terms such as 'madness' or 'getting off your brain'. Most African-Caribbean PwD said that reliance for care should be placed upon healthcare professionals, although they also said memory services are often not suitable. Some participants said that informal family care is sometimes not available, for example in the case of children setting abroad or having work and family pressures of their own. Maintaining independence was also described as important, some participants felt concerned about ending up in a care home.

Moreland (2001)	Qualitative	UK (England)	<p>Total participants: 40 (20 community representatives; 20 carers and PwD)</p> <p>African-Caribbean: 20 (n= 10 carers of PwD from the AC community, and n= 10 AC community representatives)</p> <p>South Asian: 20</p>	To determine whether there are any people with dementia who are not seeking help. To explore the level of understanding of dementia and to discuss people's experiences of services for dementia.	Community leaders explained that dementia is commonly described by stigmatising terms within the African-Caribbean community. Participants also explained that there is no word for dementia in Patois language, which may make dementia difficult to conceptualise in older African-Caribbean communities. Some community representatives said they had no awareness of dementia, and when dementia was explained to them half of them thought of people who may be showing the early warning signs of dementia. There was a general lack of understanding of available services amongst community representatives. Carers explained stress they were under caring for a PwD and expressed a need for help with physical part of caring such as bathing and dressing. Carers also thought services should be more culturally sensitive, for example offering appropriate food at day centres.
Moreland (2003)	Qualitative	UK (England)	Total participants: 18 (10 community representatives, carers and PwD from Moreland (2001), and 8 service providers)	See Moreland (2001). In addition, study aimed to follow up participants who were previously interviewed to discuss the services accessed and whether their experiences had changed	Of the African-Caribbean PwD included in the sample, none lived with or were dependent on family members. The regression to childhood type behaviours typical of dementia meant that PwD often revert to the language and behaviour they associate with their earlier days in the Caribbean. This is one of the reasons carers suggested that culturally sensitive care is important. Carers also

thought that there was a lack of sharing of information between services leading to miscommunication.

Mukadam et al. (2011)	Qualitative	UK (England)	Total participants: 18 (carers, Female-13, Male-5) White British: 4; South Asian: 5; Black African/Caribbean:5; White Irish: 1; White other: 1; Asian other: 1; Chinese: 1	To explore understanding and pathways to care for dementia in BAME and indigenous carers	Participants from BAME groups were more likely not to seek help until the PwD was exhibiting severe symptoms and problems had become unmanageable. There were also delays on the part of the PwD refusing to accept help and carers viewing outside help as intrusive. Carers also voiced concern about the stigma surrounding dementia in African-Caribbean communities. The most common care pathway was through a GP but it was also common for the PwD to have only received their diagnosis after visiting a doctor for a separate physical problem.
Parveen, Peltier & Oyeboode (2016)	Qualitative	UK (England)	Total participants: 175 (people living with dementia, carers and members of the public) British Indian: 62	To use 'Leventhal's Model of Self Regulation' to uncover the understating and experience of dementia of Caribbean, and East and Central European communities	African-Caribbean participants could describe common symptoms of dementia and assigned a biological cause but reported feeling they have a lack of knowledge about the condition. In terms of consequences of dementia, the African-Caribbean group were most concerned about the PwD wandering and getting lost. Participants also discussed the stigma surrounding dementia and how people are often ashamed to talk about it within their community. African-Caribbean people

African & Caribbean: 50
East and Central
European: 63

mentioned a number of third sector organisations as well as GPs and family when they were asked about their awareness and use of services. Participants shared the negative experiences they had with GPs such as feeling and also voiced a concern about a lack of cultural sensitivity from services.

Roche et al (2018)	Qualitative & Quantitative	UK (England)	<p>Total patients: 47 Patients from 5 GP practices.</p> <p>Black African: 23</p> <p>Black Caribbean (BC): 11 (Intervention- 6, Control-5)</p> <p>Black British: 11</p> <p>Asian Caribbean: 2</p> <p>Having known (19/47, 40.4%), cared for (10/47, 21%), or worked with (10/47, 21%) someone with dementia.</p>	<p>To (1) develop a new intervention to facilitate timely diagnosis of dementia in BACE, and (2) evaluated its acceptability and (3) its delivery in a feasibility cluster randomised controlled trial (RCT).</p>	<p>4/5 from the intervention group and 4/6 from the control group read the intervention leaflet. 4/5 & 3/6 said it made them think that either they or a relative or friend should visit their doctor about memory problems and six of them sought help.</p> <p>Participants found intervention relevant, useful, helpful, informative, and educational. They have favourable attitudes towards help-seeking for dementia from doctors. Their late presentation to dementia services may be driven by other factors than culture and may include failings in health care service provision.</p>
-----------------------	----------------------------------	-----------------	---	---	---

Tappen et al. (2011)	Qualitative & Quantitative	USA (Florida)	Total participants: 72 (Participants undergoing cognitive screening); African American: 29; African-Caribbean: 23 (Female-20, Male-3); European American: 20	To compare the explanatory models for Alzheimer's Disease (AD) of African-Americans, African-Caribbean and European-Americans	African-Caribbean participants (all first generation) had significantly more misconceptions about Alzheimer's Disease. Common misconceptions included AD is caused by 'aluminium' or a 'collapsed brain'
Tuerk & Sauer (2015)	Quantitative	UK (England)	Total participants: 460 (PwD); White British: 239; Black or Black British – Caribbean: 86; White other: 47; White Irish: 38; Black or Black British – African: 23; Asian or Asian British: 12; Other BME groups:15	To assess whether there were any differences in referral rates, cognitive scores and severity of dementia in different ethnic entering a memory service in London, UK.	On average, African-Caribbean people were diagnosed with dementia (4.5 years younger than White British people). They were also more likely to receive a diagnosis of vascular or mixed dementia. Cognitive scores were significantly lower within the African-Caribbean group which could suggest that they are entering services later, after symptoms have become more severe.

Abbreviations: PwD: Person/people with dementia; BAME: Black and minority ethnic; AD: Alzheimer's disease

Table 2: Thematic Analysis Framework

Stages	Process
Familiarising	<ul style="list-style-type: none"> • Reading full paper • Rereading and extracting key data
Generating initial ideas and themes	<ul style="list-style-type: none"> • Mapping papers for relevant data on conceptualisation and services access • Comparing data across studies and summarising
Reviewing themes	<ul style="list-style-type: none"> • Reviewing the initial ideas and the overarching themes in relation to the extracted data by two researcher independently • Discussing the themes and key data with the wider team
Describing and reporting	<ul style="list-style-type: none"> • Analyse the themes across the data set and synthesise the overall findings • Examine the themes in relation to the study objectives and research questions.

Supplementary Table 1: Search Strategy

Database	Date -last search performed	Search Terms	Results
CINAHL	02/05/2019	dementia/ or alzheimer/ and Caribbean/ Caribbean diaspora/ or African Caribbean/ or Afro Caribbean/ or Black Caribbean/ or West Indian/ or Jamaican	76
Pubmed	03/05/2019	("dementia"[MeSH Terms] OR ("alzheimer disease"[MeSH Terms] OR ("alzheimer"[All Fields] AND "disease"[All Fields]) OR "alzheimer disease"[All Fields] OR ("alzheimer's"[All Fields] AND "disease"[All Fields]) OR "alzheimer's disease"[All Fields])) AND (((("west indies"[MeSH Terms] OR "caribbean region"[MeSH Terms]) OR "west indian"[All Fields]) OR jamaican[All Fields])	137
Psychinfo	02/05/2019	<p>1. dementia.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]</p> <p>2. exp PRESENILE DEMENTIA/ or exp DEMENTIA/ or exp SENILE DEMENTIA/ or exp AIDS DEMENTIA COMPLEX/ or exp SEMANTIC DEMENTIA/ or exp DEMENTIA WITH LEWY BODIES/ or exp VASCULAR DEMENTIA/</p> <p>3. alzheimer*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]</p> <p>4. exp ALZHEIMER'S DISEASE/</p> <p>5. 1 or 2 or 3 or 4</p> <p>6. caribbean.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]</p> <p>7. (caribbean adj diaspora).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]</p>	103

		<p>8. (african adj caribbean).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]</p> <p>9. (afro adj caribbean).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]</p> <p>10. (black adj caribbean).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]</p> <p>11. (west adj indi*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]</p> <p>12. jamaica*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]</p> <p>13. 6 or 7 or 8 or 9 or 10 or 11 or 12</p> <p>14. 5 and 13</p>	
EMBASE	02/05/2019	<p>1. dementia.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading]</p> <p>2. exp HIV associated dementia/ or exp "mixed depression and dementia"/ or exp multiinfarct dementia/ or exp semantic dementia/ or exp dementia/ or exp presenile dementia/ or exp Pick presenile dementia/ or exp frontal variant frontotemporal dementia/ or exp senile dementia/ or exp frontotemporal dementia/</p> <p>3. alzheimer*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading]</p> <p>4. exp Alzheimer disease/</p> <p>5. 1 or 2 or 3 or 4</p>	529

		<p>6. caribbean.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading]</p> <p>7. exp Caribbean/ or exp African Caribbean/ or exp "Caribbean (person)"/ or exp Caribbean Islands/</p> <p>8. (caribbean adj diaspora).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading]</p> <p>9. (african adj caribbean).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading]</p> <p>10. (afro adj caribbean).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading]</p> <p>11. (black adj caribbean).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading]</p> <p>12. (west adj indi*).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading]</p> <p>13. jamaica*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading]</p> <p>14. 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13</p> <p>15. 5 and 14</p>	
Medline	02/05/2019	<p>1. dementia.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading</p>	236

		<p>word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]</p> <p>2. exp Dementia/ or exp Frontotemporal Dementia/ or exp AIDS Dementia Complex/ or exp Dementia, Vascular/ or exp Dementia, Multi-Infarct/</p> <p>3. alzheimer*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]</p> <p>4. exp Alzheimer Disease/</p> <p>5. 1 or 2 or 3 or 4</p> <p>6. caribbean.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]</p> <p>7. exp Caribbean Region/</p> <p>8. (caribbean adj diaspora).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]</p> <p>9. (african adj caribbean).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]</p> <p>10. (afro adj caribbean).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]</p> <p>11. (black adj caribbean).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept</p>	
--	--	---	--

		<p>word, rare disease supplementary concept word, unique identifier, synonyms]</p> <p>12. (west adj indi*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]</p> <p>13. jamaica*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]</p> <p>14. 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13</p> <p>15. 5 and 14</p>	
AMED	02/05/19	<p>1. dementia.mp. [mp=abstract, heading words, title]</p> <p>2. exp Dementia/</p> <p>3. alzheimer*.mp. [mp=abstract, heading words, title]</p> <p>4. exp Alzheimers disease/</p> <p>5. 1 or 2 or 3 or 4</p> <p>6. caribbean.mp. [mp=abstract, heading words, title]</p> <p>7. (caribbean adj diaspora).mp. [mp=abstract, heading words, title]</p> <p>8. (african adj caribbean).mp. [mp=abstract, heading words, title]</p> <p>9. (afro adj caribbean).mp. [mp=abstract, heading words, title]</p> <p>10. (black adj caribbean).mp. [mp=abstract, heading words, title]</p> <p>11. (west adj indi*).mp. [mp=abstract, heading words, title]</p>	1

		<p>12. jamaica*.mp. [mp=abstract, heading words, title]</p> <p>13. 6 or 7 or 8 or 9 or 10 or 11 or 12</p> <p>14. 5 and 13</p>	
Cochrane – Controlled trials	02/05/2019	<p>1. dementia.mp. [mp=title, original title, abstract, mesh headings, heading words, keyword]</p> <p>2. Dementia/ or Frontotemporal Dementia/ or AIDS Dementia Complex/ or Dementia, Vascular/ or Dementia, Multi-Infarct/</p> <p>3. alzheimer*.mp. [mp=title, original title, abstract, mesh headings, heading words, keyword]</p> <p>4. exp Alzheimer Disease/</p> <p>5. 1 or 2 or 3 or 4</p> <p>6. caribbean.mp. [mp=title, original title, abstract, mesh headings, heading words, keyword]</p> <p>7. exp Caribbean Region/</p> <p>8. (caribbean adj diaspora).mp. [mp=title, original title, abstract, mesh headings, heading words, keyword]</p> <p>9. (african adj caribbean).mp. [mp=title, original title, abstract, mesh headings, heading words, keyword]</p> <p>10. (afro adj caribbean).mp. [mp=title, original title, abstract, mesh headings, heading words, keyword]</p> <p>11. (black adj caribbean).mp. [mp=title, original title, abstract, mesh headings, heading words, keyword]</p> <p>12. (west adj indi*).mp. [mp=title, original title, abstract, mesh headings, heading words, keyword]</p> <p>13. jamaica*.mp. [mp=title, original title, abstract, mesh headings, heading words, keyword]</p> <p>14. 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13</p> <p>15. 5 and 14</p>	8

Cochrane – systematic Review	02/05/2019	<ol style="list-style-type: none"> 1. dementia.mp. [mp=title, short title, abstract, full text, keywords, caption text] 2. alzheimer*.mp. [mp=title, short title, abstract, full text, keywords, caption text] 3. (Lewy adj bodies).mp. [mp=title, short title, abstract, full text, keywords, caption text] 4. (pick's adj disease).mp. [mp=title, short title, abstract, full text, keywords, caption text] 5. (creutzfeldt adj jakob).mp. [mp=title, short title, abstract, full text, keywords, caption text] 6. (normal adj pressure adj hydrocephalus).mp. [mp=title, short title, abstract, full text, keywords, caption text] 7. huntington's*.mp. [mp=title, short title, abstract, full text, keywords, caption text] 8. wernicke-korsakoff.mp. [mp=title, short title, abstract, full text, keywords, caption text] 9. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 10. caribbean.mp. [mp=title, short title, abstract, full text, keywords, caption text] 11. (caribbean adj diaspora).mp. [mp=title, short title, abstract, full text, keywords, caption text] 12. (african adj caribbean).mp. [mp=title, short title, abstract, full text, keywords, caption text] 13. (afro adj caribbean).mp. [mp=title, short title, abstract, full text, keywords, caption text] 14. (black adj caribbean).mp. [mp=title, short title, abstract, full text, keywords, caption text] 15. (west adj indi*).mp. [mp=title, short title, abstract, full text, keywords, caption text] 	78
---------------------------------------	------------	--	----

		16. jamaica*.mp. [mp=title, short title, abstract, full text, keywords, caption text] 17. 10 or 11 or 12 or 13 or 14 or 15 or 16 18. 9 and 17	
NICE Evidence	03/05/2019	'Dementia and Caribbean'	572
Scopus	03/05/2019	(dementia OR alzheimer*) AND (caribbean OR "caribbean diaspora" OR "african caribbean" OR "afro caribbean" OR "black caribbean" OR Jamaican OR " west AND indi*) AND NOT (gene*)	111
Web of science	03/05/2019	You searched for: TOPIC: (dementia OR alzheimer*) AND TOPIC: (caribbean OR "caribbean diaspora" OR "african caribbean" OR "afro caribbean" OR "black caribbean" OR "west indi*" OR jamaica*)	260
Open Grey	03/05/2019	Dementia and Caribbean	1
British Nursing Index	03/05/2019	(dementia OR alzheimer*) AND (Caribbean OR "Caribbean diaspora" OR "African Caribbean" OR "Afro Caribbean" OR "Black Caribbean" OR "West Indi*" OR "Jamaica*")	90
Applied Social Sciences Index & Abstracts (ASSIA)	03/05/2019	(dementia OR alzheimer*) AND (caribbean OR "Caribbean diaspora" OR "African Caribbean" "Afro Caribbean" OR "Black Caribbean" "West Indi*" OR Jamaica*)	38

Supplementary Table 2: Studies for full text review

Author	Title	Decision	Notes	References
Acosta et al. (2008)	The epidemiology of dependency among urban-dwelling older people in the Dominican Republic; a cross-sectional survey	Exclude	No specific information on african-caribbeans with dementia - dependency in domican republic	
Acosta et al. (2010)	The prevalence and social patterning of chronic diseases among older people in a population undergoing health transition. A 10/66 Group cross-sectional population-based survey in the Dominican Republic	Exclude	No specific information on african-caribbeans with dementia. No details of ethnic groups included in sample and just looking at prevalence of long term diseases such as	
Adamson (1999)	Informal care of a person with dementia in families of 'Asian' and 'African/Caribbean' descent	Exclude	Exclude, thesis.	
Adamson (2001)	Awareness and understanding of dementia in African/Caribbean and South Asian families	INCLUDE	African Caribbean people's Conceptualisation of dementia	
Adamson & Donovan (2002)	Research in black and white	Exclude	Nothing about african caribbeans with dementia specifically but might have useful background information. E.g. methodological issues surrounding conducting interviews with BAME groups	
Adamson & Donovan (2005)	'Normal disruption': South Asian and African/Caribbean relatives caring for an older family member in the UK	INCLUDE	Carers experiences of looking after african caribbean person with dementia	

Adelman et al. (2009)	A systematic review of the prevalence and covariates of dementia or relative cognitive impairment in the older African-Caribbean population in Britain	Exclude	Prevalence study, mixed samples included e.g. black african and african caribbean and mixed diagnoses e.g. dementia and depression. Useful background information	Cooper et al. (2010)
Adelman et al. (2011)	Need to identify modifiable risk factors of dementia in the older UK African-Caribbean population reply	Exclude	Letters	
Adelman et al. (2011)	Prevalence of dementia in African-Caribbean compared with UK-born White older people: Two-stage cross-sectional study	Exclude	Not including prevalence studies. Nothing about understanding/services for AC people with dementia. Useful background information	
Age UK policy document	Understanding the lives of older people living with frailty : a qualitative investigation	Exclude	No specific information on african-caribbeans with dementia - some useful background information	
Al Hadithy et al. (2008)	Pharmacogenetics of Parkinsonism, rigidity, rest tremor, and bradykinesia in African-Caribbean inpatients: Differences in association with dopamine and serotonin receptors	Exclude	Genetic study looking at physical parkinson's symptoms of AC people. Not related to dementia understanding/services	
Albanese et al. (2013)	Dementia and lower blood pressure in Latin America, India, and China	Exclude	study looks at the relationship between dementia and blood pressure (BP) in 8 low- and middle income countries. Nothing about AC and dementia understanding and/or services	

Albanese et al. (2013)	Dementia severity and weight loss: A comparison across eight cohorts. the 10/66 study	Exclude	study looks at association between dementia severity and weight loss in countries with low and middle incomes. Nothing about AC and dementia understanding and/or services	
Ali & Josephs (2012)	Atypical and vascular Parkinsonism in Jamaica	Exclude	frequency, demographic and clinical features of atypical and vascular parkinsonism on the island of Jamaica - no information related to experiences, understanding or service use	
Ali & Josephs (2015)	Typical, atypical and vascular parkinsonism in Jamaica: An 8-year prospective study	Exclude	frequency, demographic and clinical features of atypical and vascular parkinsonism on the island of Jamaica - no information related to experiences, understanding or service use	
Almeida, Leite & Hildebrandt (2009)	Alzheimer's family caregivers: literature review	Exclude	Study of systematic reviews with the objective of analyzing the issues related to family caregivers of patients with Alzheimer's disease - nothing specific about african caribbean people with dementia	
Alzheimer Disease International (2013)	World Alzheimer report 2013 : journey of caring - an analysis of long-term care for dementia	Exclude	No specific information on african-caribbeans with dementia. Useful contextual/background information about dementia prevalence/incidence etc in caribbean	

Amella (1997)	Amount of food consumed by elderly nursing home residents with dementia as a function of the quality of the reciprocal relationship between nurse aide caregivers and residents, caregivers' power and empathy	Exclude	Use of Social Exchange Theory to investigate mealtime interaction between caregiver and patient. Mixed caribbean and african american sample. Nothing related to AC understanding of dementia or services used.	
Arentoft et al. (2012)	Multidimensional effects of acculturation on English-language neuropsychological test performance among HIV+ Caribbean Latinas/os	Exclude	Study looks at associations between a multidimensional acculturation measure and neuropsychological performance among 82 HIV+ Caribbean Latina/o adults. Sample did not have dementia and not specific information about african caribbeans	
Arksey et al., (2005)	Review of respite services and short-term breaks for carers for people with dementia	Exclude	No specific information on african-caribbeans with dementia	
Ashby-Mitchell et al. (2015)	Life Expectancy with and without Cognitive Impairment in Seven Latin American and Caribbean Countries	Exclude	Only CI not dementia diagnosis in sample. No reporting of AC people	

Baboolal, Davis & McRae (2014)	Trinidad and Tobago: A decade of dementia research	Exclude	Discuss- email author. Caregiving research may be relevant. Includes african descended patients and is focussed on caregiver burden but does not have any results for AC people specifically and cannot find the study's full paperNo Access	"The Plight of the Caregiver: A Study of the Burden Placed upon Caregivers of Patients with Dementia in Trinidad" ""The Prevalence of depression among the Elderly who attend Senior Activity Centres in Trinidad""
Barnaby, Sewell & Lipps (2009)	Clinical presentations of patients attending a Dementia Clinic in Kingston, Jamaica	Exclude	Poster presentation, cant find published paper	
Barnes & Brannelly (2008)	Achieving care and social justice for people with dementia.	Exclude	Not much information about african caribbeans with dementia. A few sentences about one AC going into a residential care facility because of his presumed 'risk'	
Barnes et al. (2015)	Mixed pathology is more likely in black than white decedents with Alzheimer dementia	Exclude	comparison of the burden of neuropathology in black and white participants with clinical Alzheimer disease (AD).	

Basu & Brennan (2012)	Does living in a family slow cognitive decline in dementia?	Exclude	Research presentation, focus not on african caribbean people with dementia	
Beard et al. (2009)	The two voices of alzheimer's: Attitudes toward brain health by diagnosed individuals and support persons	Exclude	No specific information on african-caribbeans with dementia	
Beaubrun (1963)	Huntington's chorea in Trinidad	Exclude	Could not access full text but does not seem relevant	
Berwald et al. (2016)	Black African and Caribbean British Communities' Perceptions of Memory Problems: "We Don't Do Dementia"	INCLUDE	Qualitative study of black african and caribbean people's attitudes towards dementia	Mukadam, Cooper & Livingston (2013); Regan et al. (2013)
Beverley et al., (2000)	Eliciting users' views of the processes of health care: a scoping study	Exclude	No specific information on african-caribbeans with dementia	
Bhugra et al. (2014)	EPA guidance mental health care of migrants	Exclude	Not related to african caribbeans and dementia	
Blansjaar et al. (2000)	Prevalence of dementia in centenarians	Exclude	Prevalence study in netherlands. No information about AC people	
Boneham et al. (1997)	Elderly people from ethnic minorities in Liverpool: Mental illness, unmet need and barriers to service use	Exclude	Includes african caribbean people in sample but not much information AC with dementia specifically Emailed author, No response - No access to paper	
Bosch-Bayard et al. (2016)	Cuba's strategy for Alzheimer disease and dementia syndromes	Exclude	Discusses dementia services in Caribbean (Cuba) Exclude on the basis of meeting on 07/06/17, Cuba not included as CARICOM member	

			and not about AC people use of services	
Botsford, Clarke & Gibb (2012)	Dementia and relationships: Experiences of partners in minority ethnic communities	INCLUDE	Qualitative study exploring the experiences of partners of people with dementia in two minority ethnic communities (African Caribbean and Greek Cypriot)	
Bowers et al., (2006)	The city 128 study of observation and outcomes on acute psychiatric wards	Exclude	No specific information on african-caribbeans with dementia	
British Academy report (2014)	If you could do one thing : nine local actions to reduce health inequalities	Exclude	No specific information on african-caribbeans with dementia	
Broughton, Keohane & Shorthouse (2012)	A future state of mind: facing up to the dementia challenge	Exclude	No specific information on african-caribbeans with dementia	
Buffel (2015)	Researching Age-Friendly Communities - Stories from older people as co-investigators	Exclude	Mixed ethnic groups, no information about understanding/services accessed by african caribbean people with dementia specifically	
Burke (1979)	Trends in Caribbean psychiatry. I: The problems	Exclude	Broad discussion of psychiatry in the caribbean, not specific to dementia	
Byrd, Sanchez & Manly (2005)	Neuropsychological test performance among Caribbean-born and US-born African American elderly: The role of age, education and reading level	Exclude	Not relevant - comparison of neuropsychological test scores of U.S.-born and Caribbean-born African American elders	

Cabrera et al (2014)	Pathogenesis and current treatment of Alzheimer's disease	Exclude	No specific information on african-caribbeans with dementia	
Camacho-Mercado & Clara (2016)	Ethnicity or location? Differential clinical profile of Alzheimer's disease among Puerto Ricans	Exclude	No specific information on african-caribbeans with dementia	
Campion & Fitch (2015) - Joing Commissioning Panel for Mental Health	Guidance for commissioning public mental health services (policy document - December 2015)	Exclude	No specific information on african-caribbeans with dementia.	
Caparros-Lefebvre et al. (1999)	Creutzfeldt-Jakob disease in French West Indies	Exclude	No specific information on african-caribbeans with dementia	
Caparros-Lefebvre et al. (1999)	Possible relation of atypical parkinsonism in the French West Indies with consumption of tropical plants: a case-control study	Exclude	case-control study looking at potential link between tropical fruit consumption and atypical parkinsonism	
Carr (2014)	Social care for marginalised communities : balancing self-organisation, micro-provision and mainstream support (Policy document)	Exclude	No specific information on african-caribbeans with dementia	
Centre for Policy on Ageing	The ageing of the ethnic minority populations of England and Wales : findings from the 2011 census (A briefing paper from the Centre for Policy on Ageing)	Exclude	Review of census data, useful for background information	

Chackkalackal (2014)	The value of peer support on cognitive improvement amongst older people living with dementia	Exclude	Possibly include -evaluation of three peer support groups for people living with dementia in extra-care housing schemes. Caribbean people included in sample but no results per ethnic group. Emailed author - No response	
Chakkalakal & Kalathil (2014) - Mental health foundation doc	Evaluation report : peer support groups to facilitate self-help coping strategies for people with dementia in extra care housing	Exclude	No specific information on african-caribbeans with dementia	
Charity funded report	Dementia Equity and Rights	Exclude	No specific information on african-caribbeans with dementia - cites some potentially relevant papers	Clayton et al. (2013); Age UK 'fit as a fiddle'; Truswell & Taverna (2015)
Chaudhuri (unpublished)	Non motor symptoms (NMS) of people with Parkinson's in black African/Caribbean and South Asian population in London: case control study and biomarkers and non motor subtypes evaluation	Exclude	Ongoing trial but does not look relevant - comparison of white, african caribbean and south asians non-motor parkinson's symptoms including dopaminergic scans of the brain (DatScan) and also in a subgroup collect blood sample for future genetic and enzyme analysis	
Chaudhuri et al. (2000)	Atypical parkinsonism in Afro-Caribbean and Indian origin immigrants to the UK	Exclude	Study looking at frequency, pattern and prevalence of parkinson's disease in Afro caribbean and Indian people in the UK.	

Chenoweth et al. (2015)	Organisational interventions for promoting person-centred care for people with dementia	Exclude	Services used by african caribbean people with dementia	
Cloos et al. (2010)	Active ageing: A qualitative study in six Caribbean countries	Exclude	Services for ageing, not services for AC people with dementia.	
Cohen (2000)	Racial differences in neuropsychiatric symptoms among dementia outpatients	INCLUDE	Comparison of african american and african caribbean sympoms of dementia. Symptomatology ethnic differences not in eligibility criteria	
Cohen, Hyland & Magai (1998)	Depression among African American nursing home patients with dementia	Exclude	Experiences of dementia - black people in USA. Would need to find out if there were african caribbean people included in study	
Cohen, Hyland & Magai (1998)	Interracial and intraracial differences in neuropsychiatric symptoms, sociodemography, and treatment among nursing home patients with dementia	Exclude	Study looks at interracial (black & white) and intra racial (african caribbean & african caribbean) differences experiences of depression, psychosis and agitation in a nursing home	
Conference abstratcs	Abstracts of the 7th World Research Congress of the European Association for Palliative Care (EAPC)	Exclude	No specific information on african-caribbeans with dementia	
Davis et al. (2007)	Potential biomarkers for dementia in Trinidad and Tobago	Exclude	biomarkers - vascular dementia and alzheimer's disease	
Davis, Baboolal & McRae (2016)	Dementia prevalence in the oldest old in trinidad and medical comorbidities	Exclude	Poster presentation - prevalence study	

De Jesus (2013)	Aging and dementia: Implications for Cuba's research community, public health and society	Exclude	Exclude (meeting 07/06/17) Cuba not CARICOM country and no focus on AC people. Review focussing on need for epidemiological research to obtain greater knowledge of the disease, improve health services, promote actions for prevention and early diagnosis, and implement a national strategy to address dementia in the Cuban population.	
De Jesus (2017)	Cuba's aging and Alzheimer longitudinal study	Exclude	No specific information on african-caribbeans with dementia	
Dementia UK guide	Dementia: workers and carers together. A guide for social care workers on supporting family and friends carers of people with dementia (dementia UK guide)	Exclude	No specific information on african-caribbeans with dementia	
Demirovic et al (2003)	Prevalence of dementia in three ethnic groups: the South Florida program on aging and health	Exclude	Prevalence study african caribbeans not included	
Denning, Jones & Sampson (2012)	Preferences for end-of-life care: A nominal group study of people with dementia and their family carers	Exclude	No specific information on african-caribbeans with dementia	
Department of Health Policy document	Closing the Gap: Priorities for essential change in mental health	Exclude	Not related to african caribbeans and dementia	

Devi et al. (2000)	Familial aggregation of Alzheimer's disease and the influence of apolipoprotein E genotype in Caucasians, African Americans, and Caribbean Hispanic populations in northern Manhattan	Exclude	Study comparing the familial aggregation and lifetime risk of AD to the age of 90 years in the first-degree relatives of patients with AD and unrelated controls among caribbean hispanics, african americans and whites	
Dickens (2009)	Public awareness of dementia : what every commissioner needs to know - alzheimers society policy doc	Exclude	No specific information on african-caribbeans with dementia	
Dixon-Woods et al., (2005)	Vulnerable groups and access to health care : a critical interpretive view	Exclude	No specific information on african-caribbeans with dementia but may be useful for broader info about african caribbean interactions with mental health services. Under useful papers tab	
Dominguez et al. (2006)	Is B vitamins deficiency associated with prevalence of Alzheimer's disease in Cuban elderly	Exclude	Vitamin D as a risk factor for high prevalence of AD in Cuba. No specific information on african-caribbeans with dementia	
Eduar Herrera Murcia et al. (2015)	Empathy in Huntington's disease families: Study in the Colombian Caribbean	Exclude	Conference abstract, not AC people with dementia	
Edwards & Morris (2007)	Alone and confused: community-residing older African Americans with dementia	Exclude	African caribbeans not specified in sample	
Eldemire (1996)	Level of mental impairment in the Jamaican elderly and the issues of screening levels, caregiving, support systems, carepersons, and female burden	Exclude	Have received paper - checked for inclusion at meeting. Not enough information about dementia	

Eldemire-Shearer et al. (2011)	Chronic disease and ageing in the caribbean: Opportunities knock at the door	Exclude	Not about AC people and dementia, about chronic disease generally, but might have useful background/contextual information	
Elliot (2016)	Poverty and mental health : a review to inform the Joseph Rowntree Foundation's Anti-Poverty Strategy	Exclude	No specific information on african-caribbeans with dementia	
Elvish et al., (2012)	Psychological interventions for carers of people with dementia: a systematic review of quantitative and qualitative evidence	Exclude	No specific information on african-caribbeans with dementia	
Erol, Brooker & Peel (2015)	Women and dementia : a global research overview - Alzheimers disease international	Exclude	Not much information on caribbean people and dementia but useful background informaiton	
Evaluation of the Workforce Development Innovation Fund	Three-year evaluation of the Workforce Development Innovation Fund, 2011/12-2013/14	Exclude	No specific information on african-caribbeans with dementia	
Ferri & Prince (2010)	10/66 dementia research group: Recently published survey data for seven Latin America sites	Exclude	Letter about prevalence study	
Ferri et al. (2011)	Tobacco use and dementia: Evidence from the 1066 dementia population-based surveys in Latin America, China and India	Exclude	Study assessing the association between tobacco consumption and dementia. No information about african caribbean people	

Ferri et al., (2009)	World Alzheimer report 2009	Exclude	Exclude as not specific information on african-caribbeans with dementia but does include useful for background information e.g. prevalence in different caribbean countries	
Figueroa et al. (2008)	Geographical differences in the occurrence of Alzheimer's disease mortality: United States versus Puerto Rico	Exclude	No specific information on african-caribbeans with dementia	
Forbat (2004)	The care and abuse of minoritized ethnic groups: the role of statutory services	Exclude	Abuse in care relationships and institutional racism. Case study of african caribbean person and housing, nothing specific about dementia/healthcare systems .	Forbat (2003)
Forbat & Nar (2003)	Dementia's cultural challenge	Exclude	Short article, mentions Jamaican woman with dementia experience of services. Cites potentially relevant DoH policy document	Department of Health (1998)

Friedemann & Buckwalter (2014)	Family Caregiver Role and Burden Related to Gender and Family Relationships	Exclude	Mixed sample but not reported by ethnic group, nothing specifically related to african caribbean/dementia, more related to gender differences in caregiving - the final sample included 38.6% White non-Hispanic caregivers; 12.2% Blacks, predominantly from the Caribbean; 30.6% Cubans; and 18.6% caregivers from other Hispanic countries in Central and South America, Mexico and Puerto Rico	
Gibson, Martin & Neita (2010)	Mental illness and public health: Exploring the role of general hospital physicians at a teaching hospital in Jamaica	Exclude	mental health services in Jamaica, mention of dementia. Decided at meeting to exclude but use for background information	
Ginneken et al. (2013)	Non-specialist health worker interventions for the care of mental, neurological and substance-abuse disorders in low- and middle-income countries	Exclude	Not AC people & dementia	
Glasby et al. (2013)	Who knows best? Older people's contribution to understanding and preventing avoidable hospital admissions	Exclude	No specific information on african-caribbeans with dementia	

Glover (2013)	Running self-help groups in sheltered and extra care accommodation for people who live with dementia : a guide (Resource pack for mental health foundation)	Exclude	Services attended by caribbeans but not specifically for african caribbean people with dementia. Case study mentions caribbean patient. Exclude, very little information about AC and dementia	
Glymour & Manly (2008)	Lifecourse Social Conditions and Racial and Ethnic Patterns of Cognitive Aging	Exclude	lifecourse framework. Mention of caribbean and dementia. Exclude, not dementia, cognitive aging and focus on African Americans, no mention of Caribbean background	
Goldstein et al. (2014)	Validity of the montreal cognitive assessment as a screen for mild cognitive impairment and dementia in African Americans	Exclude	Assessing validity of a measure with african americans. Exclude.	
Gonzalez et al. (2014)	Building capacity for dementia care in Latin America and the Caribbean	Exclude	Excude on the basis of meeting 07/06/17 - no focus on AC people. Useful paper for background info though. Latin America and the Caribbean - reviewing existing initiatives and provided examples of actions taken to build capacity and improve the effectiveness of individuals, organizations, and national systems that provide treatment and support for people with dementia and their caregivers. However not specifically about african caribbean people and their experiences with services	

Gonzalez et al. (2015)	Global comparisons for developing a national dementia registry in Cuba	Exclude	Exclude on the basis of meeting 07/06/17 - no focus on AC people and Cuba not a CARICOM member. Paper addresses the Cuban proposal for an automated national dementia registry, comparing it to others internationally	
Gottesman et al. (2015)	Brain Aging in African-Americans: The Atherosclerosis Risk in Communities (ARIC) Experience	Exclude	Exclude, African American sample, no mention of AC people/dementia. Review discusses the experience in the Atherosclerosis Risk in Communities (ARIC) study evaluating racial disparities relating to stroke, subclinical brain infarction, leukoaraiosis, as well as cognitive change and dementia	
Grant (2016)	Using Multicountry Ecological and Observational Studies to Determine Dietary Risk Factors for Alzheimer's Disease	Exclude	Study looks at cross cultural dietary practices and risk of AD. No reference to AC people and dementia	
Gray et al. (2014)	Satisfaction with social care services among black and ethnic minority populations : exploring satisfaction with adult social care services amongst Pakistani, Bangladeshi and white British people (NatCen social research document)	Exclude	No specific quotes about african caribbean people with dementia, but included in sample/focus group. Email for further info?	

Greene, Pugh & Roberts (2008)	SCIE Research briefing 29: Black and minority ethnic parents with mental health problems and their children	Exclude	The briefing does not include older people (those aged 65 and over), dementia, detailed evaluations of services and interventions, or experiences of particular services.	
Greenwood et al. (2016)	Qualitative focus group study investigating experiences of accessing and engaging with social care services: perspectives of carers from diverse ethnic groups caring for stroke survivors	Exclude	Mixed ethnicity focus group, related to stroke survivors not focussed on dementia experiences and services	
Grelotti et al. (2015)	A Pilot Initiative to Deliver Community-based Psychiatric Services in Rural Haiti after the 2010 Earthquake	Exclude	Not specific to dementia but evaluation of psychiatric care in the caribbean	
Guartazaca Gerrero et al. (2016)	Behavioral and psychological symptoms in elderly patients with dementia: A 5-year cohort follow up	Exclude	Exclude, poster presentation and not AC people. Follow up of patients with dementia in cuba to assess patterns of behavioural and psychological symptoms.	
Hall et al. (2000)	Community screening interview for dementia (CSI 'D'); performance in five disparate study sites	Exclude	Exclude, cross cultural evaluation of a measure	
Hall et al. (2011)	Feasibility, acceptability and potential effectiveness of Dignity Therapy for older people in care homes: A phase II randomized controlled trial of a brief palliative care psychotherapy	Exclude	Exclude, no focus on AC/dementia	
Harvey et al., (2005)	Measuring outcomes for carers for people with mental health problems	Exclude	Review of outcome measures, no specific information on african caribbeans with dementia	

Hasan et al. (2015)	The UK's contribution to health globally : benefiting the country and the world - A report by the All-Party Parliamentary Group on Global Health	Exclude	Discusses building public health capacity twinning PHE with the Seychelles, Sierra Leone and Trinidad and Tobago (through the Caribbean Public Health Association, CARPHA, and linking to other countries in the Caribbean), also involving Canada as a partner	
Health & Social Care Information Centre	Focus on dementia	Exclude	No specific information on african-caribbeans with dementia	
Health & Social Care Information Centre	Focus on the Health and Care of Older People - June 2014	Exclude	No specific information on african-caribbeans with dementia	
Hendrie (2009)	Diagnosis of dementia and Alzheimer's disease in Indianapolis and IBADAN: Challenges in cross-cultural studies of aging and dementia	Exclude	Taken from a research symposia - challenges related to cognitive assessments for different cultural groups	
Hendrie et al. (1996)	Cross-cultural perspectives: Caribbean, Native American, and Yoruba	Exclude	Review of cultural differences in relation to behavioural disturbances and treatment approaches for dementia - Jamaican sample. Email author for more information?	
Hendrie et al. (2015)	Statin use, incident dementia and Alzheimer disease in elderly African Americans	Exclude	Not specific to AC people with dementia. Looks at the association between statin use, incident dementia, and Alzheimer disease (AD) in a prospective elderly African American cohort.	

Hinojosa et al. (2009)	Racial/ethnic variation in recovery of motor function in stroke survivors: role of informal caregivers	Exclude	Related to motor function and caring for stroke survivors. Mixed ethnicity sample. Cites potentially relevant paper	Janevic & Connell (2001)
Hoban et al. (2011)	Voices on well-being: A report of research with older people	Exclude	No specific information on african-caribbeans with dementia	
Honyashiki et al. (2011)	Chronic diseases among older people and co-resident psychological morbidity	Exclude	psychological morbidity with chronic diseases across Cuba, dominican rep, peru, venezuela, mexico, china and india	
House of Commons All-Party Parliamentary Group on Dementia report (2013)	Dementia does not discriminate: the experiences of black, Asian and minority ethnic communities	INCLUDE	Include? Different BAME groups but Includes results specifically about african caribbean people's experiences of dementia and engagement with services.	
House of Commons Committee of Public Accounts	Improving access to mental health services. Sixteenth Report of Session 2016-2017	Exclude	No specific information on african-caribbeans with dementia but useful for intro	
Housing LIN' case study	The benefits of extra care housing on the quality of life of residents: The impact of living in Campbell Place, Fleet	Exclude	No specific information on african-caribbeans with dementia	
Huxley et al., (2011)	Integration of social care staff within community mental health teams (NIHR report)	Exclude	No specific information on african-caribbeans with dementia	Robertson-Hickling, Abel & Hickling (2008)
Jackson et al., (2012)	The Mental Health Act 2007 : a review of its implementation	Exclude	No specific information on african-caribbeans with dementia	

Joint Commissioning Panel for Mental Health	Guidance for commissioners of mental health services for people from black and minority ethnic communities	Exclude	Focusses on African caribbeans experiences and services related to psychosis, nothing specifically about dementia?	
Jolley et al. (2009)	The 'Twice a Child' projects: learning about dementia and related disorders within the black and minority ethnic population of an English city and improving relevant services	Exclude	Overview of the three 'twice a child' projects - reviews and interviews with african caribbean and asian communities in Wolverhampton. Include full papers - see ref lists. This is an overview of the projects, include full papers in review, use this for discussion of twice a child projects	Moreland, Jolley & Read (2005); Dementia plus (2001; 2003; 2007)
Jordanova et al. (2007)	Markers of inflammation and cognitive decline in an African-Caribbean population	Exclude	Biomarkers/inflammatory processes and dementia - prospective association between levels of three markers of inflammation, plasma interleukin-6 (IL-6), serum C-reactive protein (CRP), serum amyloid A (SAA), and cognitive decline in an African-Caribbean community population	
Josephs et al. (2016)	Frontotemporal dementia in patients of African descent	Exclude	Conference abstract - brain anatomy african descended people with dementia	

Jutlla (2013)	Ethnicity and cultural diversity in dementia care: a review of research	Exclude	Could not access full text but potential include. Gained access 19/05/17 nothing additional about AC and dementia. Cites twice a child projects. Useful background/contextual information though	
Kalaria et al. (2008)	Alzheimer's disease and vascular dementia in developing countries: prevalence, management, and risk factors	Exclude	No specific information on african-caribbeans	
Karlawish et al. (2011)	What Latino Puerto Ricans and non-Latinos say when they talk about Alzheimer's disease	Exclude	Not AC people/dementia. Latino Puerto Ricans and Non-Latino White caregivers	
Katzenschlager et al (2003)	Unclassifiable parkinsonism in two European tertiary referral centres for movement disorders	Exclude	Study looking at non classifiable parkinsons patients. Not related to dementia/AC people	
Keane (2005)	A comparison of the Boston Naming Test and Miami Naming Test in an Afro-Caribbean population over the age of 55	Exclude	Thesis - african caribbean sample but just looks at scores on two different measures	
Keane et al. (2015)	Comparison of African American and Afro-Caribbean older adults' self-reported health status, function, and substance use	Exclude	Useful background information but no information about dementia	
Keating et al., (2006)	Research priorities for service user and carer-centred mental health services : a synthesis of the literature	Exclude	No specific information on african-caribbeans with dementia	Keating et al., (2002)

Kelley (2005)	Gendered elder care exchanges in a Caribbean village	Exclude	Exclude, focus is on gender differences and care of the elderly. Nothing about AC people and only one mention of alzheimers. Elderly care in a village in St Lucia although not reported to be dementia services specifically	
Khan & Venneri (2011)	Fewer paris, parrots peaches: Interpreting cross-cultural semantic fluency deficits in Alzheimer's assessment	Exclude	Poster presentation, Differences in fluency deficits in caribbean and british people with dementia. Include? Different experiences of dementia	
Khan & Venneri (2012)	Culture matters: Clarifying the effect of ethnicity on memory and attention and its implications for assessment of Alzheimer's disease	Exclude	cultural differences in neuropsychological assessments - british and caribbean participants	
Khan, Shanks & Venneri (2009)	The influence of education and ethnicity on mini mental state examination (MMSE) scores	Exclude	Not AC experiences/services - dementia	
Knight et al., (2007)	Mental health and physical health of family caregivers for persons with dementia: a comparison of African American and white caregivers	Exclude	African caribbeans not specified in sample	
Koss-Chioino (2003)	Jung, spirits and madness: Lessons for cultural psychiatry	Exclude	Not AC experiences/services - dementia	
Lai et al. (2012)	Special care units for dementia individuals with behavioural problems	Exclude	Not AC experiences/services - dementia	

Lannuzel et al. (2015)	Clinical varieties and epidemiological aspects of amyotrophic lateral sclerosis in the Caribbean island of Guadeloupe: A new focus of ALS associated with Parkinsonism	Exclude	Not related dementia - experiences of/services. ALS association with Parkinsons in Guadeloupe	
Lawrence et al. (2008)	Attitudes and support needs of Black Caribbean, south Asian and White British carers of people with dementia in the UK	INCLUDE	Includes information about carers of African Caribbean people with dementia	Milne & Chrysanthopoulou (2005); Dilworth-Anderson & Gibson (2002); Lawton et al. (1992); Connell & Gibson (1997); Haley et al. (1996); Atkin & Rollings (1992)
Lawrence et al. (2011)	Threat to Valued Elements of Life: The Experience of Dementia Across Three Ethnic Groups	INCLUDE	Experiences of dementia: AC, south asian and white british	
Levine et al. (2015)	Does Stroke Contribute to Racial Differences in Cognitive Decline	Exclude	Not related to AC dementia/experiences of services. Study looks at whether racial differences in cognitive decline are explained by differences in the frequency or impact of incident stroke between blacks and whites	
Lievesley & Midwinter (2013)	Wellness : prevention and the sustainability of health and well-being in older age	Exclude	No specific information on african-caribbeans with dementia.	

Lipman & Manthorpe (Age UK policy document)	Gearing up: Housing Associations' responses to tenants with dementia from black and minority ethnic groups, October 2015	Exclude	Exclude, mention of a services used by african caribbean people with dementia. Limited information though	
Lippa (2011)	Review of issue: Caregiver depression and a plan to manage resistance to care	Exclude	Nothing related to african caribbeans and dementia but cites Tappen (included paper)	
Livingston (unpublished)	Improving dementia care in African and Caribbean minority ethnic groups	Exclude	Project relevant but in process. No access	
Livingston et al. (2001)	Mental health of migrant elders - the Islington study	Exclude	Exclude (prevalence study) but useful background information. Study compares prevalence of dementia and depression in older migrants with those born in the UK. Compared with those born in the UK, the prevalence of dementia was raised in African-Caribbeans	
Livney et al. (2011)	Ethnoracial Differences in the Clinical Characteristics of Alzheimer's Disease at Initial Presentation at an Urban Alzheimer's Disease Centre	Exclude	Exclude due to reported sample - African American, Latino (primarily of Caribbean origin), and white non-Hispanic ("WNH") subjects	Manly & Mayeux (2004)
Llibre (2011)	Dementia and other chronic diseases in older adults in Havana and Matanzas: the 10/66 study in Cuba	Exclude	Looks at prevalence of risk factors. Includes structured physical and neurological exams	
Llibre Guerra et al. (2016)	Prevalence, incidence and associations between APOE genotype, cardiovascular risk factor and dementia in the Cuban population	Exclude	Prevalence/genetic study. Not AC experiences/services - dementia	

Llibre Jde et al. (2009)	Prevalence of dementia and Alzheimer's disease in a Havana municipality: A community-based study among elderly residents	Exclude	prevalence study, not AC people	
Local government association	Working with faith groups to promote health and wellbeing	Exclude	No specific information on african-caribbeans with dementia	
Maayan, Soares Weiser & Lee (2014)	Respite care for people with dementia and their carers	Exclude	not AC people/dementia	
Maestra & Nitrini (2014)	It is time to focus on an underestimated epidemic	Exclude	Editorial re. dementia epidemic in LAC. Exclude, nothing related to AC people/dementia experiences/services. Includes countries not in CARICOM	
Maestre (2008)	Dementia in Latin America and the Caribbean: An overlooked epidemic	Exclude	Comment but suggests resources that are needed to prevent and treat people with dementia in LAC, use for background information? Nothing about AC people	
Mak, Kim & Stewart (2006)	Leg length, cognitive impairment and cognitive decline in an African-Caribbean population	Exclude	Exclude, not related to AC/dementia/services. Looks at early life/trauma, leg length and cognitive reserve. 'In a community population of African-Caribbean elders, in whom leg length had been measured, study seeks to compare associations with cognitive impairment at baseline and cognitive decline over a three-year follow-up period.'	Stewart & Richards (2002)

Manes (2016)	The huge burden of dementia in Latin America	Exclude	Correspondance - exclude but useful background information	
Manly et al. (2008)	Frequency and course of mild cognitive impairment in a multiethnic community	Exclude	Nothing specific to AC/dementia	
Manly et al. (2011)	Telephone-Based Identification of Mild Cognitive Impairment and Dementia in a Multicultural Cohort	Exclude	Study looks at accuracy of a telephone interview in classifying people with dementia. Not related to AC/dementia specifically	
Marcheco et al. (2003)	Attitudes and knowledge about presymptomatic genetic testing among individuals at high risk for familial, early-onset Alzheimer's disease	Exclude	Exclude, Attitudes of Cuban family before diagnosis of alzheimers	
Maurer (2011)	Education and Male-Female Differences in Later-Life Cognition: International Evidence From Latin America and the Caribbean	Exclude	Nothing specific to AC/dementia	
Mavrodaris, Powerll & Thorogood (2003)	Prevalences of dementia and cognitive impairment among older people in sub-Saharan Africa: A systematic review	Exclude	Nothing specific to AC - sub saharan africa	
Maxwell (2005)	Extra care housing options & older people with functional mental health problems (DoH fact sheet)	Exclude	No specific information on african-caribbeans with dementia, related to people's long-standing Functional Mental Health problem such as depression, schizophrenia and anxiety as they get older.	
McCracken et al (1997)	Prevalence of dementia and depression among elderly people in Black and ethnic minorities	Exclude	Exclude, no results for AC specifically. Focus of paper is on	

			depression amongst elderly people with dementia	
Mcintosh (2008)	Under the radar	Exclude	Short article discussing the lack of mental health services for black and minority ethnic older people. The article does include a relevant service though - the Caribbean Dementia Cafe run by Leeds Black Elders Association	
McKenzie & De Santi (2011)	Beliefs about cognitive loss among older African-and caribbean-American adults	Exclude	Poster presentation - No access to full paper	
McNally (2015)	Levels of cognitive impairment among elders in cuba: Findings from the survey on health, well-being, and aging in latin america and the caribbean (SABE)	Exclude	Poster presentation - assessing cuban elders for cognitive impairment	
Mehta & Yeo (2017)	Systematic review of dementia prevalence and incidence in United States race/ethnic populations	Exclude	Prevalence study, no data for AC populaton	
Mental Health Foundation. (2016)	Fundamental facts about mental health 2016 - policy document	Exclude	No specific information on african-caribbeans with dementia	
Mitrani et al. (2005)	Adapting the structural family systems rating to assess the patterns of interaction in families of dementia caregivers	Exclude	Development pf a measure (SFSR-DC) using sample of Cuban Americans and white non hispanic participants	

Mitrani et al. (2008)	Conflict resolution and distress in dementia caregiver families: Comparison of Cubans and white non-hispanics	Exclude	Study investigates the role of family conflict resolution as a mediator of the relationship between ethnicity and psychological distress in dementia caregivers.	
Molero, Pino-Ramirez & Maestre (2007)	High prevalence of dementia in a Caribbean population	Exclude	Prevalence study - caribbean people in the caribbean. Useful background information	
Moriarty (2008)	The health and social care experiences of black and minority ethnic older people	Exclude	Information about african caribbean is not relevant e.g. about hypertension and relevant information is a replication of findings of other ncluded studied e.g. Lawrence	Moriarty & Butt (2004); Rai-Atkins et al., (2002)
Moriarty & Manthorpe (2012)	Diversity in older people and access to services - an evidence review, 2012 (age UK report)	Exclude	Limited information on african-caribbeans with dementia, information about experiences of BME groups broadly. Useful contextual/backgroup paper	McLeod et al., (2008); 'Cass Business school' (2012)
Mukadam, Cooper & Livingston (2010)	A systematic review of ethnicity and pathways to care in dementia	Exclude	systematic review including different ethnic groups but has data specifically related to AC people with dementia	Hinton, Franz & Friend (2004)
Nadkarni et al. (2011)	The psychological impact of heavy drinking among the elderly on their co-residents: The 10/66 group population based survey in the Dominican Republic	Exclude	Not related to AC people with dementia. Study examines prevalence of heavy drinking amongst the elderly in dominican republic and severity of	

			psychological and behavioural symptoms	
Neal & Barton Wright (2009)	Validation therapy for dementia	Exclude	cochrane systematic review of validation therapy, nothing specific to AC people with dementia	
Neita et al. (2014)	The prevalence and associated demographic factors of dementia from a cross-sectional community survey in Kingston, Jamaica	Exclude	Prevalence study, nothing specific to AC people with dementia. Broadly looks at prevalence in a jamaican population and western european population	
Nervi et al. (2008)	Comparison of Clinical Manifestations in Alzheimer Disease and Dementia With Lewy Bodies	Exclude	Exclude, study looks at neuropsychological profiles in DLB and AD among Caribbean Hispanic family members and participants in a population-based epidemiologic sample using extended neuropsychological test batteries and to explore whether these differences were related to heritable factors.	
Network for mental health - policy doc'	Mental Healthwatch handbook : improving mental health with your community	Exclude	No specific information on african-caribbeans with dementia	
Newbronner et al. (2013)	A road less rocky: supporting carers of people with dementia (carers trust guide)	Exclude	No specific information on african-caribbeans with dementia.	

Ngandu, Mangialasche & Kivipelto (2014)	The Epidemiology and Prevention of Alzheimer's Disease and Projected Burden of Disease	Exclude	Not related to AC people with dementia.	
Nguyen et al. (2008)	Life course socioeconomic disadvantage and cognitive function among the elderly population of seven capitals in Latin America and the Caribbean	Exclude	study looks at life course socioeconomic disadvantages (SED) on cognitive function in later life - caribbean and latin america. Nothing specific about AC people	
NHS report	Compassion in practice : two years on	Exclude	Not related to african caribbeans and dementia	
NHS report	The five year forward view mental health taskforce : public engagement findings - A report from the independent Mental Health Taskforce to the NHS in England September 2015	Exclude	No specific information on african-caribbeans with dementia	
Nicholson et al., (2008)	Croydon Rethink African and Caribbean Carers Support Group - Mental Well-being Impact Assessment (MWIA)	Exclude	Write up of a support group meeting for african and caribbean carers. Exclude, not focussed on dementia and mixed black african and caribbean population	
Nielsen & Waldemar (2016)	Knowledge and perceptions of dementia and Alzheimer's disease in four ethnic groups in Copenhagen, Denmark	Exclude	AC people not included in study. Native Danes, Polish, Turkish and Pakistani immigrants	
NIH bypass budget proposal for fiscal year 2018	Stopping Alzheimer's disease and related dementias: advancing our nation's research agenda. NIH bypass budget proposal for fiscal year 2018	Exclude	No specific information on african-caribbeans with dementia	

O'Shea et al. (2015)	Examining the association between late-life depressive symptoms, cognitive function, and brain volumes in the context of cognitive reserve	Exclude	Not related to dementia, AC people not included in sample. Hispanic, African American, and non-Hispanic White sample.	
Orr (2010)	The pursuit of certainty in diagnosing dementia: Cognitive testing, childishness and stress in two British memory clinics	Exclude	Not related to AC people with dementia.	
Oxford Dementia Challenge Group - evaluation paper	Evaluation of Oxfordshire dementia-friendly communities project	Exclude	No african caribbean people included in sample	
Pagan-Ortiz et al. (2014)	Use of an online community to provide support to caregivers of people with dementia	Exclude	Development of a website for spanish speaking caregivers. Not AC population.	
Paradise et al. (2009)	Systematic review of the effect of education on survival in Alzheimer's disease	Exclude	No results specific to AC population with dementia	
Parsons et al., (2010)	Self-management support among older adults : the availability, impact and potential of locally based services and resources	Exclude	No specific information on african-caribbeans with dementia	
Parveen, Peltier & Oyebode (2016)	Perceptions of dementia and use of services in minority ethnic communities: a scoping exercise	INCLUDE	Culturally specific dementia awareness roadshows. British Indian, African and Caribbean, East and Central European attenders. Has results/quotes from AC people experiencing dementia/caring for someone with dementia	Johl, Patterson & Pearson (2016)

Perez et al. (1996)	Towards community diagnosis of dementia: Testing cognitive impairment in older persons in Argentina, Chile and Cuba	Exclude	No information about african-caribbeans with dementia	
Perry, Barner & England (2013)	A review of values-based commissioning in mental health (network nsun for mental health report)	Exclude	Exclude, does mention that there should be more reseach into older african caribbean people's mental health but limited information	
Pierre & Meastre (2013)	Dementia care in haiti: Needs and opportunities for capacity building	Exclude	Exclude, Poster presentation. Assessment and experiences of people in Haiti with dementia, nothing about AC people.	
Policy doc - department of health and human services centers for disease control and prevention	Trends in aging -- United States and worldwide	Exclude	No specific information on african-caribbeans with dementia	
Policy doc - NHS Quality Improvement Scotland 2005	Report of the Scoping Study Group on the Provision of Spiritual Care in NHS Scotland Sep 2005	Exclude	No specific information on african-caribbeans with dementia	
Policy document - carers UK	Half a million voices : improving support for BAME carers	Exclude	Exclude, experiences of african caribbean carers, useful background information	
Policy document - DoH	New Horizons: A shared vision for mental health: EqIA (DH)	Exclude	No specific information on african-caribbeans with dementia	
Policy document - Nuffield Council on Bioethics	Dementia : ethical issues	Exclude	No specific information on african-caribbeans with dementia	

Policy document - WHO	Equity, social determinants and public health programmes	Exclude	No specific information on african-caribbeans with dementia	
Policy document - WHO	Global health and aging	Exclude	No specific information on african-caribbeans with dementia	
Prakash (2011)	Need to identify modifiable risk factors of dementia in the older UK African-Caribbean population	Exclude	Exclude, Correspondance - critique of adelman's prevalence study. Could be useful for discussion/background info	
Prince (2009)	Treatment for patients and caregivers in the developing world	Exclude	Plenary, no data AC/dementia	
Prince et al. (2003)	Dementia diagnosis in developing countries: a cross-cultural validation study	Exclude	No results specific to AC population with dementia	
Prince et al. (2004)	Care arrangements for people with dementia in developing countries	Exclude	Use for background information. NOthing about ethnic background of the samples and more focussed on Latin American countries. A descriptive and comparative study of dementia care, caregiver characteristics, the nature of care provided, and the practical psychological and economic impact upon the caregiver in 24 centres in India, China and South East Asia, Latin America and the Caribbean and Africa	
Prince et al. (2007)	The protocols for the 10/66 dementia research group population-based research programme	Exclude	Incidence study. No results specific to AV people & experiences of dementia	

Prince et al. (2011)	A brief dementia screener suitable for use by non-specialists in resource poor settings--the cross-cultural derivation and validation of the brief Community Screening Instrument for Dementia	Exclude	Development of dementia screener. No results specific to AC people & experiences of dementia	
Prince et al. (2011)	Leg length, skull circumference, and the prevalence of dementia in low and middle income countries: a 10/66 population-based cross sectional survey	Exclude	Study carried out in India, China, Cuba, Dominican Republic, Venezuela, Mexico and Peru. Nothing specific to AC people with dementia	
Prince et al. (2011)	The association between common physical impairments and dementia in low and middle income countries, and, among people with dementia, their association with cognitive function and disability. A 10/66 Dementia Research Group population-based	Exclude	Study carried out in India, China, Cuba, Dominican Republic, Venezuela, Mexico and Peru. Nothing specific to AC people with dementia	
Prince et al. (2012)	Dementia incidence and mortality in middle-income countries, and associations with indicators of cognitive reserve: A 10/66 Dementia Research Group population-based cohort study	Exclude	Incidence study. No results specific to AV people & experiences of dementia	
Prineas et al. (1995)	South Florida Program on Aging and Health. Assessing the prevalence of Alzheimer's disease in three ethnic groups	Exclude	Prevalence study, not specified AC people - African American, Cuban American and white non-Hispanic American	

Rait et al. (2000)	Screening for cognitive impairment in older African-Caribbeans	Exclude	Useful background information but paper not relevant. Testing the efficacy of measures in an AC community - MMSE & AMT	
Rankin (2005)	Mental health in the mainstream	Exclude	No specific information on african-caribbeans with dementia	
Rawlins (2001)	Caring for the chronically ill elderly in Trinidad: The informal situation	Exclude	Cant access full text but abstract could be relevant. Includes afro-trinidadian carers. Not sure whether study looks at dementia though. Checked in meeting not related to dementia care specifically, exclude	
Rawlins et al. (2015)	Attitude towards Alzheimer's disease among undergraduate students of university of the West Indies, Trinidad and Tobago	Exclude	Attitudes/conceptualisation of dementia in west indies. Not related to AC people and dementia	
Razzouk et al. (2008)	Challenges to reduce the '10/90 gap': Mental health research in Latin American and Caribbean countries	Exclude	Not specific to AC with dementia. Mental health research generally across latin america and caribbean	
Rechel et al., (2011)	Migration and health in the European Union (policy document)	Exclude	No specific information on african-caribbeans with dementia	
Regan (2016)	The interface between dementia and mental health : an evidence review	Exclude	No specific information on african-caribbeans with dementia	
Report from the WHO European Ministerial Conference	Mental health: facing the challenges, building solutions	Exclude	No specific information on african-caribbeans with dementia	McClean, Campbell & Cornish (2003)

Repper et al., (2008)	Family carers on the margins : experiences of assessment in mental health	Exclude	Some discussion of african caribbeans experiences with services generally. Nothing specific to african caribbean patients or carers and dementia	
Ribeiro et al. (2016)	Non-pharmacological strategies used to manage the behavioral alterations in the elderly with dementia	Exclude	Selected conference abstract. Not relevant AC/dementia	
Richards & Brayne (1996)	Cross-cultural research into cognitive impairment and dementia: Some practical experiences	Exclude	Includes discussion of african caribbean migrants to UK and dementia. Focus on cognitive impairment rather than dementia but may have useful background information	Richards et al. (1995)
Richards et al. (2000)	Cognitive function in UK community-dwelling African Caribbean and white elders: A pilot study	Exclude	Exclude, as per other Richards paper, focus on cognitive impairment but may be useful for background information. Assessments with african caribbean and white elders. Rated by a psychiatrist blinded to ethnicity	
Rodriguez et al. (2008)	The Prevalence, Correlates and Impact of Dementia in Cuba	Exclude	Not relevant AC/dementia	
Ross et al., (2009)	The professional experience of governance and incentives: meeting the needs of individuals with complex conditions in primary care	Exclude	No specific information on african-caribbeans with dementia	

Roush et al. (2013)	Exemplars of geriatric education centers in geriatric psychiatry programming on mental health issues in later life	Exclude	AAGP annual meeting' not relevant AC/dementia	
Rowe et al. (2014)	Alzheimer's disease and other dementia in sub-Saharan Africa and the Caribbean	Exclude	Letter to editor not specific to AC people. Mainly focussed on death rates in Subsaharan africa & caribbean	
Sachrajda (2011)	Dementia care in London (policy document - institute for public policy research)	Exclude	No specific information on african-caribbeans with dementia - useful background info	
Salazar, Dwivedi & Royall (2017)	Cross-ethnic differences in the severity of neuropsychiatric symptoms in persons with mild cognitive impairment and Alzheimer's disease	Exclude	Not AC with dementia. Hispanics vs non hispanic whites	
Santini et al. (2014)	Helping Haiti: Addressing the burden of neurologic disease	Exclude	Couldn't find new text but potentially relevant from reading abstract, includes burden of dementia in haiti aswell as other neurological diseases. Received 19/05/17 - poster presentation, no mention of AC/dementia exclude.	
Santoso et al. (2016)	HIV-associated dementia in the Dominican Republic: A consequence of stigma, domestic abuse and limited health literacy	Exclude	Nothing specific to AC people in the paper but paper is about HIV related dementia in the caribbean and barriers to seeking help, DR not CARICOM counry	
Santoso, Erkinen & Adon (2016)	The Montreal cognitive assessment may not be an effective screening tool in low income countries with education inequality	Exclude	Poster, study assessing use of MOCA at an infectious disease clinic in Santo Domingo, Dominican Republic.	

Sayegh & Knight (2013)	Cross-cultural differences in dementia: the Sociocultural Health Belief Model	Exclude	Some discussion of AC people with dementia but model is broadly a conceptual framework for examining cross-cultural differences in dementia care-seeking among diverse groups. Useful theory/background information	Dilworth et al. (2008); Dilworth-Anderson et al. (2008); Gray et al. (2009); Hinton et al. (2005)
Sepulveda et al. (2015)	Un Cafe Por El Alzheimer: An innovative awareness approach in Puerto Rico	Exclude	Cant access full article. Access to check for inclusion. Received from doc supply, exclude - poster presentation, service in caribbean but nothing about options re/its use by AC people. Also Puerto Rico not CARICOM country	
Shah (2007)	Can the recognition of clinical features of mental illness at clinical presentation in ethnic elders be improved	Exclude	Not specific to AC with dementia. BME groups generally. Might be useful for background/intro info	
Shah et al., (2009)	CR156. Psychiatric Services for Black and Minority Ethnic Older People	Exclude	Royal College of Psychiatrists report. Discusses AC people and dementia. Discusses papers that are already included (e.g. Lawrence) and is not focussed on dementia but has useful background information	Richards et al (1998)
Shah, Dalvi & Thompson (2005)	Is there a need to study behavioral and psychological signs and symptoms of dementia across cultures?	Exclude	Letter, not specific to AC people	

Sharan et al. (2009)	Mental health research priorities in low- and middle-income countries of Africa, Asia, Latin America and the Caribbean	Exclude	Nothing specific to AC people with dementia	
Skills for care	Dementia and diversity : a guide for leaders and managers	Exclude	Guide, limited information about AC people and dementia services.	
Sleath et al. (2004)	Medication use among black and white caregivers of older male veterans with dementia	Exclude	cant access full text. Gain access to check for inclusion. Screened at meeting exclude.	
Sleath et al. (2005)	African-American and white caregivers of older adults with dementia: Differences in depressive symptomatology and psychotropic drug use	Exclude	Not AC/dementia experiences/services	
Sosa et al. (2012)	Prevalence, distribution, and impact of mild cognitive impairment in Latin America, China, and India: A 10/66 population-based study	Exclude	Not AC/dementia experiences/services	
Spencer et al., (2010)	The role of migrant care workers in ageing societies : report on research findings in the United Kingdom, Ireland, Canada and the United States (policy document - international organization for migration	Exclude	No specific information on African-Caribbean with dementia - useful background info	
Stella et al. (2015)	Caregiver report versus clinician impression: Disagreements in rating neuropsychiatric symptoms in Alzheimer's disease patients	Exclude	Not AC/dementia experiences/services	

Stevens, Leavey & Livingston (2004)	Dementia and hypertension in African/Caribbean elders	Exclude	study examined the association between country of birth and type of dementia in a representative community sample of people aged 65 years and older in Britain. - AC people & dementia	
Stewart et al. (2001)	Apolipoprotein E genotype, vascular risk and early cognitive impairment in an African Caribbean population	Exclude	Genetic study. Reduced risk of AD associated with the apolipoprotein E (APOE) allele	
Stewart et al. (2001)	Cognitive function in UK community-dwelling African Caribbean elders: Normative data for a test battery	Exclude	Cognitive tests with African Caribbean sample and comparison with other ethnic groups. But differences in cognitive ability/symptomatic differences is not in eligibility criteria. (Subsequent study to Richards et al.) Also not focussed on dementia, focus on cognitive function and cultural differences. Possibly useful background information	
Stewart et al. (2001)	Depression, APOE genotype and subjective memory impairment: A cross-sectional study in an African-Caribbean population	Exclude	Genetic study. APOE genotype, depression and memory impairment in AC population	

Stewart et al. (2001)	Vascular risk and cognitive impairment in an older, British, African-Caribbean population	Exclude	Exclude, looks at associations between hypertension etc and cognitive impairment -Participants interviewed and examined for cardiovascular risk factors, including a blood test for lipid profile and fibrinogen. A battery of 11 psychometric tests was administered blind to medical status. Cognitive impairment was defined on the basis of a composite measure derived from individual test scores.	
Stewart et al. (2002)	The distribution of Mini-Mental State Examination scores in an older UK African-Caribbean population compared to MRC CFA Study norms	Exclude	Description of normalities data for the mini-mental state examination (MMSE) in a UK African-Caribbean populationand comparison with norms for white UK born elders	
Stewart et al. (2004)	ACE genotype and cognitive decline in an African-Caribbean population	Exclude	Genetic study	
Stewart, Guerchet & Prince (2016)	Development of a brief assessment and algorithm for ascertaining dementia in low-income and middle-income countries: The 10/66 short dementia diagnostic schedule	Exclude	Study is developing and evaluating a short version of the 10/66 dementia diagnostic schedule for use in low-income and middle-income countries - not related to AC and dementia specifically	

Stewart, Prince & Mann (2003)	Age, Vascular Risk, and Cognitive Decline in an Older, British, African-Caribbean Population	Exclude	Study investigates associations between baseline factors and subsequent cognitive decline in an older African-Caribbean population	
Stock & Lambert (2011)	Who cares wins? Carers' experiences of assessment since the introduction of the Carers (Equal Opportunities) Act 2004	Exclude	No specific information on african-caribbeans with dementia	
Strech (2013)	The full spectrum of ethical issues in dementia care: Systematic qualitative review	Exclude	Not related to AC people with dementia	
Suh et al. (2009)	International price comparisons of Alzheimer's drugs: A way to close the affordability gap	Exclude	Study looks at costs of AD drugs in different countries. Inc caribbean (dominican republic)	
Tang et al. (2001)	Incidence of AD in African-Americans, Caribbean Hispanics, and Caucasians in northern Manhattan	Exclude	Exclude, incidence rates for AD among elderly African-American, Caribbean Hispanic, and white individuals and to determine whether coincident cerebrovascular disease contributes to the inconsistency in reported differences among ethnic groups	
Tappen, Gibson & Williams (2011)	Explanations of AD in Ethnic Minority Participants Undergoing Cognitive Screening	INCLUDE	Includes results AC people's understanding/explanatory models of AD. Sample includes African Americans, African Caribbeans and European Americans	

Taylor et al. (2013)	Midlife Hypertensive Status and Cognitive Function 20 Years Later: The Southall and Brent Revisited Study	Exclude	Study investigates long term prospective associations between a range of measurements of hypertensive status in midlife and cognitive impairment 20 years later - cohort study. Multiethnic population	
Taylor et al. (2015)	Treatment for dementia : learning from breakthroughs for other conditions - policy research	Exclude	No specific information on african-caribbeans with dementia	
Taylor, Albanese & Stewart (2012)	The association of dementia with upper arm and waist circumference in seven low- and middle-income countries: the 10/66 cross-sectional surveys	Exclude	Not related to AC people with dementia	
Taylor, Chatters & Jackson (2007)	Religious and spiritual involvement among older African Americans, Caribbean Blacks, and non-Hispanic Whites: Findings from the National Survey of American Life	Exclude	Black caribbeans included in sample. Religious and spiritual involvement of older people in different ethnic groups - caribbean black, non-hispanic white and african americans. Exclude but may have some useful background info	
Teruel et al. (2011)	Interactions between genetic admixture, ethnic identity, APOE genotype and dementia prevalence in an admixed Cuban sample; a cross-sectional population survey and nested case-control study	Exclude	Genetic study - APOE-e4 allele	

Thawani, Schupf & Louis (2009)	Essential tremor is associated with dementia Prospective population-based study in New York	Exclude	Not AC & dementia. Study looks at whether essential tremor is associated with prevalent and incident dementia in an ethnically diverse sample of elders.	
The (2008)	In death's waiting room: living and dying with dementia in a multicultural society	Exclude	Exclude - Book	
The Campaign to End Loneliness policy document	Alone in the crowd: loneliness and diversity	Exclude	No specific information on african-caribbeans with dementia - some useful background information	
The Condition of Britain (report)	The generation strain : collective solutions to care in an ageing society	Exclude	No specific information on african-caribbeans with dementia	
Thiyagarajan, Prince & Webber (2014)	Social support network typologies and health outcomes of older people in low and middle income countries-A 10/66 Dementia Research Group population-based study	Exclude	Assessing construct validity of wenger social support network typology in low and middle income countries	
Tibbs (1996)	Amos: a self lost and found	Exclude	Personal accouunt discussing lack of culturally sensitive services for people from ethnic minority groups. Nothing specific to AC people and dementia	
Tolosa, Calandrella & Gallardo (2004)	Caribbean parkinsonism and other atypical Parkinsonian disorders	Exclude	Not AC people & dementia	
Tosto et al. (2015)	Admixture analysis of Alzheimer's disease in caribbean hispanics	Exclude	Podium presentation, genetic study (APOE-e4) not AC people & dementia	

Townsend (2003)	Scoring trends on the rey-osterrieth Complex Figure Test within both normal and Dementia of the Alzheimer's type Caribbean-Hispanic populations	Exclude	Thesis, caribbean hispanics scoring trends on the 'CFT'. Not AC people & dementia	
Truswell (2013)	Black, Asian and minority ethnic communities and dementia : where are we now? (A Race Equality Foundation Briefing Paper)	Exclude	Includes information about services available to african caribbeans with dementia and useful background information	Truswell (2011)
Truswell (2016)	Communities can't be left to 'look after their own'	Exclude	Exclude but use for background. Paper describes how 'culture dementia UK' works to raise awareness about dementia in the African-Caribbean and other UK minority ethnic communities. Get access. Received 19/05/17 - include, discusses cultural issues related to AC people and their understanding of dementia and experiences of services	Not a research article
Tuerk & Sauer (2015)	Dementia in a Black and minority ethnic population: Characteristics of presentation to an inner London memory service	INCLUDE	Study examines data on referrals to a memory clinic in london to explore any differences in referral rates, cognitive assessments and stages of dementia between ethnic groups - AC people included/ experiences of services	Mukadam et al. (2011); La Fontaine et al. (2007); Moriarty, Sharif & Robinson (2011); Daker-White et al. (2002)

Unverzagt et al. (1999)	Clinical utility of CERAD neuropsychological battery in elderly Jamaicans	Exclude	Study examines efficacy of the consortium to establish a registry for alzheimer's disease (CERAD) neuropsychological battery in Jamaican men and women	
Vardarajan et al. (2014)	Age-specific incidence rates for dementia and Alzheimer disease in NIA-LOAD/NCRAD and EFIGA families: National Institute on Aging Genetics Initiative for Late-Onset Alzheimer Disease/National Cell Repository for Alzheimer Disease (NIA-LOAD/NCRAD) and Estudio Familiar de Influencia Genetica en Alzheimer (EFIGA)	Exclude	Not AC people & dementia	
Vardarajan et al. (2015)	Inbreeding among Caribbean Hispanics from the Dominican Republic and its effects on risk of Alzheimer disease	Exclude	Not AC people, only caribbean hispanics included	
Whitfield et al. (2008)	Blood pressure and memory in older African Americans	Exclude	Not AC people, and dementia. African americans and cognitive functioning	
WHO report (2012)	Dementia : a public health priority	Exclude	No specific information on african-caribbeans with dementia. Useful contextual/background information about dementia prevalence/incidence etc in caribbean	
WHO report (2015)	WHO World report on ageing and health - 2015	Exclude	No specific information on african-caribbeans with dementia	
Wiley (2012)	Cuba's Integrated Health Care	Exclude	No informaion related to AC & dementia	

Williams et al. (2001)	Obtaining family consent for participation in Alzheimer's research in a Cuban-American population: Strategies to overcome the barriers	Exclude	Not AC people & dementia, Cuban Americans	
Williams et al. (2001)	Willingness to be Screened and Tested for Cognitive Impairment: Cross-Cultural Comparison	Exclude	Includes AC people; comparison of different ethnic groups in willingness to be tested for cognitive impairment - not about dementia though. Use for background information	
Williamson (2012)	Ripple on the pond. DEEP : the engagement, involvement and empowerment of people with dementia in collective influencing. Appendix to main report : a stronger collective voice for people with dementia	Exclude	Appendix and no specific information on african-caribbeans with dementia	
Wilmo & Prince (2010)	World Alzheimer report 2010 : the global economic impact of dementia	Exclude	Exclude as not specific information on african-caribbeans with dementia but does include useful for background information e.g. prevalence in different caribbean countries	
Wilmo, Winblad & Jonsson (2010)	The worldwide societal costs of dementia: Estimates for 2009	Exclude	Not AC people & dementia. Useful background/contextual information	
Wong et al. (2016)	Food insecurity is associated with subsequent cognitive decline in the Boston Puerto Rican health study	Exclude	Not AC people & dementia - puerto rican sample	

Woodall et al., (2010)	Barriers to participation in mental health research : are there specific gender, ethnicity and age related barriers?	Exclude	No specific information on african-caribbeans with dementia	
Woods et al. (2009)	Reminiscence therapy for dementia	Exclude	Not AC people & dementia. Systematic review of reminiscence therapy for dementia	
Wortmann (2016)	Global dementia policy overview	Exclude	Poster presentation - useful background/contextual information	
Ye et al. (2013)	Mediterranean Diet, Healthy Eating Index 2005, and Cognitive Function in Middle-Aged and Older Puerto Rican Adults	Exclude	Not AC people & dementia - puerto rican sample	
Yenkamala et al. (2013)	A pilot study: ayurvedic approach on memory stimulation in the french west indies	Exclude	Not AC people & dementia	
Zahodne et al. (2015)	Is residual memory variance a valid method for quantifying cognitive reserve? A longitudinal application	Exclude	Not AC people & dementia	
Bridges et al (2018)	Implementing the Creating Learning Environments for Compassionate Care (CLECC) programme in acute hospital settings : a pilot RCT and feasibility study	Exclude	Not focused on dementia in AC population	
Manthorpe J. et.al (2019)	Service provision for older homeless people with memory problems : a mixed-methods study	Exclude	No details of ethnicity for participating homeless	
Livingston G et.al (2017)	Dementia prevention, intervention, and care	Exclude	No reference to AC community	

NIHR (2017)	Getting help for forgetfulness.	Exclude	Leaflet not a research study	
Foreman K et.al (2018)	Forecasting life expectancy, years of life lost, and all-cause and cause-specific mortality for 250 causes of death: references and alternative scenarios for 2016–40 for 195 countries and territories. The Lancet.	Exclude	Not AC people & dementia	
Hill-Dixon A et.al (2018)	Being well together: the creation of the Co-op Community Wellbeing Index.	Exclude	Dementia isn't the focus nor discussed in detail per AC community	
Parveen & Oyebode (2018)	Dementia and minority ethnic carers.	Exclude	Briefing paper-no primary research or consultation findings	
The British Psychological Society (2018)	Dementia, accessibility and minority groups	Exclude	Briefing paper-no primary research or consultation findings	
LGA (2018)	Dementia support guide for councils.	Exclude	No details of AC participation in the community action project	
Graham et al (2018)	An evaluation of a near real-time survey for improving patients' experiences of the relational aspects of care : a mixed-methods evaluation.	Exclude	Not AC people & dementia	
The mental health foundation and Housing & care (2018)	An evaluation of the Standing Together project	Exclude	No details of how many AC participants were with dementia or carers, no reference to dementia	

Koffman J (2018)	Dementia and end of life care for black, Asian and minority ethnic communities.	Exclude	Briefing paper, no primary research or consultation findings	
Gridley et al (2019)	Specialist nursing support for unpaid carers of people with dementia : a mixed-methods feasibility study	Exclude	Results don't discuss AC specific data. Author's response: The proportion of carers in the survey carried out who reported themselves as from any BAME population was too small (2.5% of those who answered the question, n= 11) to allow separate analysis. Further sub-division into an African Caribbean category would be even less meaningful (0.7%, n=3) and sharing the data would compromise confidentiality.	
Fischer et al (2019)	Evaluation of technology-enabled collaborative learning and capacity building models	Exclude	Not AC people & dementia	
NIHR(2019)	How can we improve dementia care in UK black elders?	Exclude	Flyer, part of IDEMcare study which is included	
Ashby-Mitchell, K. & Anstey (2017)	The proportion of dementia in Barbados explained by common modifiable lifestyle factors.	Exclude	discusses risk factors based on data obtained from other studies (reviewed for inclusion in the search conducted in 2017) and not primary study.	

Azhar M et.al (2017)	Increased reporting accuracy of Alzheimer disease symptoms in Caribbean Hispanic informants.	Exclude	Caribbean Hispanic data combines Dominica, Puerto Rico and Cuba. Doesn't discuss the Dominica data independently. Puerto Rico and Cuba not a part of Caricom countries.	
Boboolal et al (2018)	Comparisons between different elements of reported burden and common mental disorder in caregivers of ethnically diverse people with dementia in Trinidad	INCLUDE		
Bhagirathan et al (2018)	A grounded theory analysis of the experiences of carers for people living with dementia from three BAME communities: Balancing the need for support against fears of being diminished	INCLUDE		
Brown & Murphy (2018)	Barriers to informal caregiving of persons living with dementia in Barbados: A phenomenological inquiry	INCLUDE		

Burholt et al (2018)	Social support networks of older migrants in England and Wales: the role of collectivist culture	Exclude	Doesn't discuss dementia. It's a generic paper discussing support networks for older people from ethnic backgrounds	
Charles et al (2017)	Knowledge barriers to identifying Alzheimer's disease incidence in Grenada, West Indies.	Requested full text	No response	
Davis et al (2017)	Dementia prevalence in a population at high vascular risk: the Trinidad national survey of ageing and cognition	Exclude	Prevalence study	
Dooley et al (2017)	Involving patients with dementia in decisions to initiate treatment: effect on patient acceptance, satisfaction and medication prescription	Exclude	AC specific results not discussed	
Eldemire-shearer et al (2018)	Dementia among older persons in Jamaica: Prevalence and policy implications	Exclude	prevalence study	
Epps et al (2019)	Who's Your Family?: African American Caregivers of Older Adults With Dementia	Exclude	Doesn't discuss AC population	
Godaert et al (2017)	Adapting the mini mental status to the context of the West-Indies	Exclude	Full paper in French, English version not available and abstract doesn't clarify if it has made any difference in detection of dementia	
James et al (2019)	'Challenges in Defining Inappropriate Medication Use in Parkinson Disease Dementia	Exclude	Tests the validity of MMSE in Jamaican context, doesn't address study objectives	

Mantovani et al (2017)	Engaging communities to improve mental health in African and African Caribbean groups: a qualitative study evaluating the role of community well-being champions.	Exclude	Doesn't have any reference to dementia	
Mawaka et al (2017)	Exploring the lived experience of the individual of black ethnicity living with dementia: A phenomenological study	Requested full text	No response	
Mukadam et al (2019)	Ethnic differences in cognition and age in people diagnosed with dementia: A study of electronic health records in two large mental healthcare providers	Exclude	Results don't discuss AC specific data, combines all black ethnicity	
Parra et al (2018)	Dementia in Latin America Assessing the present and envisioning the future	Exclude	Review	
Patterson et al (2017)	Dominica dementia foundation report	Exclude	Full text not available, Report not a research. Abstract doesn't describe process and methods of public involvement in dementia awareness which was the core objective of the project.	
Roche et al (2017)	The IDEMCare Study -Improving Dementia Care in Black African and Caribbean Groups: A feasibility cluster randomised controlled trial.	INCLUDE		
Taylor et al (2017)	Extended Family Support Networks of Caribbean Black Adults in the United States.	Exclude	No reference to dementia	

Victor et al (2019)	Exploring intergenerational, intra-generational and transnational patterns of family caring in minority ethnic communities: the example of England and Wales	Exclude	Not dementia specific. Study doesn't discuss how many of AC people caring responsibilities towards PwD or explore care giving in dementia.	
Zuniga et al (2017)	The Respect for Autonomy in The Management of the Elderly with Dementia	Exclude	Conference abstract Full article not available	